



*"The story of Naseema Hurzuk is not that of her alone. It is reflective, in more ways than one, of the trials and tribulations of millions of Indian disabled people. Naseema is an exceptional individual. She has not merely lived. She has reached out, influenced other disabled people and has in turn, taught them to lead a productive life."*

Javed Anis, Convenor, Disabled Rights Group

*"I have never met anyone like Naseema – a lady who simply threw away her disability to enhance her own life and that of others. 'You lack nothing, you are only different,' is her valuable mantra. A rare and insightful book."*

Anant Dixit, Editor, Kolhapur Sakal

**Naseema** is the touching personal narrative of a wheelchair-bound paraplegic woman who led a normal and healthy life till the age of sixteen. Rarely do we get such an intimate glimpse into the inner life of a disabled person. From bewilderment at first and then suicidal depression, to coping and then rising from the ashes, her story is primarily one of transcendence – how she transcended her own disability by taking on the pain of other disabled people. This truthful story reveals her own grinding personal struggle, her fights against societal apathy towards disability, unbelievable bureaucratic hurdles, lack of simple physical access and inclusivity, and finally her indomitable grit and determination that propelled her to be a beacon of compassion and strength for her fellow disabled. Naseema sits in a wheelchair but walks taller than most of us.

Naseema is the founder of Helpers of the Handicapped in Kolhapur, Maharashtra, and has won numerous awards for her outstanding work.

The book was originally written in Marathi. Very few people outside the Marathi readership therefore, knew the story of Naseema. We hope this English translation will carry Naseema's story to the whole world.

**Aasha Doodhar**, the translator, is deeply interested in Marathi literature. Her special interests cover philosophy, the arts and development issues. She lives in Delhi.



The Viveka Foundation

A CENTRE FOR ALTERNATIVE PERSPECTIVES

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# naseema

the incredible story



With Love.  
*Mumtaz*  
27-6-2007.

**naseema**  
The Incredible Story



Mama Cash, the world's first independent funding organisation for women, strives for a peaceful and just world where women are free to make their own choices and to develop their myriad talents and skills. It is for these reasons that Mama Cash supports women's groups that blaze the trail with self-initiated projects. The fact that Mama Cash supports groundbreaking projects initiated by new and local women's groups sets it Mama Cash apart from other grant making organisations.

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# **naseema**

The Incredible Story

translated from the marathi by  
**AASHA DEODHAR**

edited by  
**RUKMINI SEKHAR**

The logo for The Viveka Foundation, featuring a stylized lotus flower with five petals.

**The Viveka Foundation**  
A CENTRE FOR ALTERNATIVE PERSPECTIVES

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democratic values, pluralistic tradition, human rights, gender equality, and cultural,  
ecological and spiritual heritage. We oppose all forms of political, developmental,  
economic, linguistic and ethnic hegemony.

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• Foreword •

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There are very few Indian books on disability.

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Books by disabled Indians are even fewer. This

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lack of disability literature in India has always

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disturbed me. I remember my days spent in US

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libraries, where at the stroke of a button, the

computer would spew out a list of hundreds of books on the issues of disability—books for disabled people, on disabled people, by disabled people—simply put, books, books and more books. Literature reflects the maturity of people and the times they live in. Therefore, perhaps the absence of much published work here in India on disability is a reflection of our society and the times our disabled people live in.

India gained independence in 1947. By and large we were then a backward nation of poor, if not hungry people—fiercely nationalistic and phenomenally proud. The vision of Pandit Nehru and the wisdom of Indira Gandhi set us firmly on the path of progress. In the next fifty years, we became self-sufficient in food, ensured electricity to many of our villages, built highways, sent our man into space, and later, even exploded the nuclear bomb.

Democracy not just survived in India (whereas it didn't in most of our neighbourhood), but it actually flourished. The common man realised the value of his vote. The politician cleverly converted the votes into a vote bank. Minorities were pampered and were rewarded with "packages." It didn't matter whether the "minority" was religious, say like the Muslims; or regional, say like Punjab or Uttaranchal; or a caste or a tribe or even a profession, say farmers or lawyers or media persons. As long as they were a vote bank, rather, as long as they were *seen* as a possible vote bank by the politician, they were courted and wooed.

Those groups who saw themselves as a "minority" and felt neglected by the politician, ensured that they got the necessary attention by indulging in protest. The protest would invariably be non-violent first, as in dharnas, sit-ins and hunger strikes and later turn towards violence, which would start first with the burning of tyres and then buses. If even this did not work, then for sure more protests would follow, violence would now turn ugly, police would end up firing and a few protestors would die. This time, the politician surely would take notice, an emissary would be sent or the politician may decide to go himself to mediate. Negotiations would take place and almost definitely, the protesting minority would be rewarded with assurances, money, more assurances and actual schemes.

The disabled people of India were doubly unlucky. Neither did the politician look upon them as a "minority" (and therefore a vote bank) nor did the disabled population leverage themselves as one. And this happened despite their being *six* per cent of India's total population! *Seventy million* disabled Indians are more than the entire population of say, Great Britain or Canada or several of our neighbouring countries

put together. And yet, they were severely neglected by India's policy makers and decision makers. What is worse is the fact that they tolerated this monumental neglect and quietly suffered. Who does one blame—the Indian nation and its bureaucrats and politicians or the disability sector and its so-called leadership or lack of it?

But before we fix the blame, let's examine this—less than two per cent of disabled children and youth have access to education, less than one per cent of disabled men and women have regular jobs, there is hardly any access to either the built environment or to basic transportation systems like the roadways or the railways, there is no specialised health care, aids and appliances are simply not available, the few that are 'Made in India' are of extremely bad quality—the list is endless.

The story of the disabled Indian is basically the story of gross neglect. How did it happen? More importantly, how did we allow it to happen? Well yes, we can blame the callous politician or the insensitive bureaucrat or even society at large. But what about us —We the *disabled* people of India? Our leadership? Where were they? What were they upto in the fifties, sixties, seventies and even in the 1980s?

A quick look into the past of the Indian disability sector would reveal a saga of decadence, of an extremely narrow vision, of a self-serving attitude. In the process, land at prime locations got allocated, huge multi-storeyed buildings got constructed, grants in lakhs if not crores were cornered, but alas, the lot of the disabled did not change. By and large, they remained where they were. Shackled and seeped in poverty with almost zero hope. To be born disabled in India became a curse.

While poverty was a raging national issue, nobody focused on disability as a definitive cause. It never was on the agenda, never a part of the discourse. The fact that disability and poverty complement and feed each other was never highlighted.

Disability was not on the agenda of the Council of Architecture, nor on that of the National Institute of Design till the 1990s. Even the University Grants Commission was not aware. As a result, *all* our universities and colleges are totally inaccessible and disabled-unfriendly. Our leaders were happy just setting up special schools—one after the other, mindlessly, perhaps heartlessly.

Critical national organisations like the Planning Commission of India, the National Human Rights Commission or the Census Commission were

also equally unaware. As a result, the total allocation on disability at the central level was a mere 470 million rupees until 1996. Disability was not on the agenda of the National Human Rights Commission till 1998. And questions on disability were not listed on the National Census till 2001.

It was only towards the end of 1995 that the country's Parliament passed a law. The Disability Act, as it is referred to, has been there on paper since the last nine years but has hardly been implemented. I have been and am firmly of the view that even if ten per cent of it is faithfully implemented, the lot of our disabled people would begin to change. However, sheer inertia on the part of the bureaucrats in the Ministry of Social Justice and overall political apathy has ensured that the law itself became "handicapped."

The story of Naseema Hurzuk is not that of her alone. It is reflective, in more ways than one, of the trials and tribulations of millions of Indian disabled people—to become disabled, to encounter suicidal depression, but then to conquer it and to move on in life. Naseema, of course, is an exceptional individual. She has not merely lived. She has reached out, influenced other disabled people and has in turn, taught them how to live a productive life.

I am personally very happy that Naseema's book, originally written in Marathi, has been translated into English and edited with a lot of love and care by the Viveka Foundation. The translator and the editors, and all others associated with the project deserve a very special thanks from all of us in the Indian disability sector. I hope that this book is widely disseminated—not so much within the disability sector but outside—into the corridors of the Government of India, deep inside the corporate world, amongst our friends in the mass media. The more it is read, the more it will convert people to the issue of disability.

Frankly, what we need now is a mini revolution. Not many people in India know that yellow is the colour of disability. And so, I will suggest that after having experienced the Green Revolution, leading to self sufficiency in food, the White Revolution leading to self sufficiency in milk and milk products, it is time now for our country to undergo a *Yellow Revolution*! We need to create a disabled-friendly India. We *have* to create a disabled-friendly India. We have no choice.

JAVED ABIDI

CONVENOR, DISABLED RIGHTS GROUP  
NEW DELHI, INDIA

Karkare at an event organised by Helpers of the Handicapped, an institution in Kolhapur, a small Indian town in the state of Maharashtra.

*Then from the dew drops of tears  
We'll create beautiful rainbows...  
With the threads of joys and sorrows  
We'll weave the fabric of our own life.*

The only person who truthfully epitomises every single word in this poem is Naseema Hurzuk, the founder of Helpers of the Handicapped. I have never met anyone like her—a lady who simply threw away her own disability to enhance her life and those of innumerable others like her. With her help they now stand on their own, have self-confidence and self-respect. “You lack nothing, you are only different” is a valuable mantra she has given them and by which they now live.

Naseema Didi wrote a column called *From the Wheelchair* for the Sunday edition of the *Kolhapur Sakal* for a whole year—articles that pushed and prodded your complacency, disturbed you and made you restless. She wrote about her fights and struggles with disability, her dreams of empowerment of the disabled, her endless efforts to actualise them, her determination, truthfulness and strict discipline. How could this woman on a wheelchair accomplish what an able person couldn't do? How imperfect we are even with our able bodies!

The past thirty-four years have seen Naseema Didi on a wheelchair. She has been witness to her own body crying defeat and endured wounds full of blood and pain. Sleepless nights, unbearable pain, cramps, inability to carry out normal bodily functions—Didi had to go through several such phases. But she never became disheartened and never once went back on her mission to help the disabled.

*Naseema* is an autobiographical account of her life, a panorama of her life's struggles, punctuated with incidents and episodes. The book is living testimony to her oath, “Never cry, never lose heart.”

Fortunately, Naseema Didi was not alone. Her family stood by her as did people like Manohar Deshbhratar and PD Deshpande who, it seemed, were sent by heaven to sustain her. Didi's challenge became theirs.

• introduction •

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A particular word gets its real meaning only

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from actual life as it is experienced and

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understood. Till such time, it remains merely a

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word. This struck me twelve years ago when I

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heard the mellifluous voice of Rajanitai

Once Didi asked me a question. I couldn't have answered her even if I was reborn several times over. It was about a year and a half ago and she had severe pain in her arm. Didi said, "It's been almost thirty-two years. My body has no sensation waist down. I've been living with only half a body. Now my arm hurts. Suppose I was to be struck down with another kind of handicap, should I live any longer?"

But I would tell her, again and again, with all my heart, that she was not alone. You may have half a body, but your mind lives in so many disabled people who live and bloom because of your love and example. You have been the human hand holding up the Govardhan Mountain of fortitude for the disabled. You simply have to be there for them.

Disabled people have to suffer not just the pain of their bodies but also their minds. Society can be cruel. Didi's experiences have been both sweet and sour; as you read about them, you are sometimes overcome by anger, at other times you can't stop your own tears. A human being can be extremely inhuman. Even the cruelest, most shattering experiences did not kill her humanity just like the tree that stands in the sun offering shade to the scorched passer by. Didi is that tree.

Helpers of the Handicapped is the story of unparalleled struggle. Each hurdle, and there were hundreds of them, was crossed with an enthusiasm that was unique to Didi. Her job extended to finances, understanding human minds, even getting aggressive at times. Naseema Didi is a rebellion. A rebel never gives up. Maybe that incident in school when she refused to yield to the whims of a handful of troublesome boys sowed the seeds of rebellion in her life. Fatalistic sentences like "How strange are the ways of destiny" become meaningless, for Didi is a living example of the Upanishads, the Bible and the Qu'ran.

Honouring her word is of paramount importance to her. The other day PD Deshpande joked, "If Didi was told to stand up and pull down that thing on the wall, saying that it was of great importance to Helpers, she would, well, *stand up!*"

What is life without a sense of touch? Is it not the greatest source of joy? We find many reasons to cry. But when half your body is dead and the other half lashed with endless pain, how can you not cry and keep

smiling? When half your body is a senseless stone, can you swim in the ocean? If you can, it certainly means something. When the wheelchair is your life companion, how can you cross the seven seas and become a sports hero in a foreign land? When you have no fingers on your hand or, in fact, no hand at all, how can a Mohammad write with his feet and inaugurate a building for Helpers? Naseema Didi has answers.

*Naseema* is an immortal tale of struggle, propelled only by faith in life. It is not just a story, it is real. It is pain, fresh air, inspiration, and a new world. In publishing this book, Anil Mehta and his son, Sunil have offered new hope to humanity, indeed to life itself. The Marathi reader (and now, the English reader) is privy to Didi's unique life. The narration is not flashy but an honest effort to reach both the able and the disabled. The book comes wrapped with a special ribbon—a sincere wish for those struggling with disabilities—how to avoid the pitfalls Naseema Hurzuk went through.

ANANT DIXIT  
EDITOR  
KOLHAPUR SAKAL

• Editor's Note •

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After finishing the editing of this book, I sat

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down and took a really long breath. Naseema's

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personal narrative about her life is one of the

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most truthful stories I've ever read. This is the

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story of a highly sensitive woman who often

steps aside from her flow of life to take stock—sometimes with gravity and at other times with humour, sometimes with tearful vulnerability and at other times with iron determination, sometimes clumsily but at other times with amazing dexterity. As dexterously as she manoeuvres her wheelchair in which she is fated to spend her entire life. This is the story of Naseema the woman, Naseema the paraplegic and Naseema the woman-paraplegic.

I first heard about this book when our long standing colleague and friend Aasha Deodhar asked me whether I'd heard of Naseema who was considered somewhat of a miracle worker in her home state of Maharashtra in India. I believe that she had published a hugely popular autobiography in Marathi, her native language. As soon as I had some idea of what was in the book I was determined to have it translated into English and publish it. For Naseema's is a story that should be read by people everywhere, not just by those who know Marathi.

This is, in the ultimate analysis, a story of joy and hope sprinkled generously with the grim suffering of disability. When the knowledge of affliction is certain, whether it is cancer, aids or a serious disability issue like paraplegia, there are those who yield to their ravages through the dark alley of despondency and there are others who embrace the affliction and make a radical shift towards learning, acceptance, fighting and transcendence and also switching on a few street lights in that dark alley. Naseema clearly did all of the latter.

Her personal story takes us through the entire landscape of what is commonly known as "disability issues." Yes, all that we hear and read about is real. For instance, just a simple flight of stairs which we take so much for granted, is the most daunting obstacle for a person on a wheelchair. For this simple architectural feature vetoes access and makes him or her immediately dependent on a helper. Indian trains are a disabled person's nightmare as we see from Naseema's innumerable journeys which she undertook for her work. And like all small worlds, the world of the disabled has its nether side rife with corruption and brutality. Quite simply put, it is well nigh impossible for a disabled person in this country to just "have a good time."



To be disabled in India is bad enough, but to be poor and disabled (and a woman) is pure hell. So that is where Naseema turns her gaze. We see, among other things, how important corrective surgeries and using prostheses or artificial devices at the right age are, how poor disabled children are discarded as trash by mainstream organisations, how vital it is to nurture the heart and emotions of disabled people, how disabled women are often sexually abused and why challenged children should be included in “normal” schools. With disarming humour we are also told that disabled people can also be up to a lot of mischief, have their fair share of peccadilloes and are by no means saints.

We are ever so grateful that Mama Cash, an independent funding organisation for women, found our book worthy of their generous support. Throughout the production of this book, Naseema herself has been of great help answering our several queries again and again.

We hope that this translation will help the people of the world get to know Naseema better, empower disabled women and men to take charge of their lives, and construct a gentle ramp towards understanding their special needs.

RUKMINI SEKHAR  
THE VIVEKA FOUNDATION



A child, about six years old, is fast asleep on a bed in front of me. This is Avinash Dahat from Amarawati who has no hands. He studies in class one and sings with full-throated ease. His feet are his hands—if I drop my comb or pen by mistake, his feet dart forward in a flash to pick it up. A troublesome heckler is warded off with a rapier-like thrust of the feet or better still, he just bites them. His demeanour is never despondent. He is a bit of a nag

though, constantly following me around till I leave the hostel, asking, "Didi, will you come back in the evening?" When I don't return, he sleeps alone on my bed. On World Handicapped Day, Avinash, with his wonder-feet lit the inaugural lamp on the stage. No one was surprised. Avinash has taught me so much that he is my guru these days.

Today is one of those days when I reminisce on the canvas of my life. And today is also when I decided to write a book on the story of my life in deference to all those who have been goading me to do so. Not only do I want society to know what a disabled person goes through, but I hope that in some way it will be a positive pointer for their rehabilitation.

I have never believed in astrology. As a child, when I was told by an astrologer that I would be a great author, I laughed. I believed then as I do now, that authors are people who whisk you away to an imaginary fairy tale world of happiness, far away from the real world. But I'm not that kind of an author, I can only write about the real world of my experiences.

Once, it so happened that a palmist came to our office.

"Come on Naseem, show him your hand," my colleagues nudged me.

"But you know what I feel about all this," I said, my skepticism obvious.

"Oh come on, don't be a damp squib!"

"Okay, okay," I said hesitantly, extending my palm.

"Mmmmm," he pondered scratching his chin, "Mmmmm, sorry, but you will not get married. The joy of married life is not your destiny."

"Oh that really surprises me!" I said sarcastically. "But, of course, you haven't inferred that from my wheelchair, have you? I guess I didn't need your astrological skills to tell me that!"

He ignored my sarcasm, continuing, "You're going to build a big house."

I burst out laughing, "Ha, I will not marry, I will have no child and I have a government job. What will I build this big house for? Rent?"

Poor fellow, my cynicism was too much for him. All of a sudden he said, "I'll come back soon," and left in haste without seeing anyone else's hands. He never returned. I hadn't even paid him.



This evening, as the sun sets and I look at the large hostel building and reminisce on the past, present and future, the palmist, whose face or name I can't remember, floats into my thoughts. How I wish he was here now to see this "House of Courage" as I call it. My apologies to you, sir, for making fun of you!

As I go way back into my childhood, the first thing I recall is that I was the only dark one in my family. Ma and Baba and my siblings were all very fair. Baba's first wife died when my elder brother was just a baby of two and a half. He married again because it was difficult to bring up three daughters and a son all by himself. Then came the four of us—three sisters and a brother. We were such a tight, close-knit family that until I was in class nine, I didn't even know I had stepsisters and a stepbrother. Our family is still very close.

Often, when we had visitors, someone would ask Ma, pointing at me, "Halin-bi, is this one yours?"

"Yes," Ma said.

"But...er...Halin-bi, she looks so different. You and your husband are fair, then how come she's so da..?"

Before they could say the word "dark" they saw Ma's eyes and my sad face, they would say consolingly, "She has your features though."

My father used to hug my eldest sister, Rehana a lot more than he did all of us. Maybe because she looked a lot like him—fair, big built, bold and intelligent. Besides, she had top grades in school. Did I really belong to this family? Maybe they were being so good to me because I was an orphan. Obviously they didn't want me to know, so I got food and clothing like the others. Once, Rehana told me that I was bought in exchange for some grain husk. That did it. I was now sure of my orphaned status, or else, how could I be so different from the rest of my family in nature and appearance?

I was not much of a talker, so my silence often invited scoldings whether I had done any wrong or not. But Rehana would argue and retaliate and so she would actually be punished more often. If I was upset I would sit quietly, cleaning rice.

A pattern emerged. Every time there were guests, I began to sit alone in the darkest room in the house. I dreaded hearing the same question they asked Ma each time, "Is this one



yours....?” I wouldn’t come out even when I was called. To avoid eating with the guests, I would eat just rice and dal as soon as it was cooked and pretend to be fast asleep. Many years later, when people began asking Rehana the same thing about *her* daughter, Humera, who, like me, was also dark, I knew how to handle it with a deft dose of child psychology and a terse reply. Rehana, my tit-for-tat, spitfire sister, now needed some lessons herself on how to deal with such questions!

When I was a young girl, our father was a Superintendent in the Central Excise Department. I noticed how the other Inspectors’ children sported a lavish lifestyle, smart clothes and plenty of pocket money and once asked Baba, “How is it that though you are a higher officer in rank you have less money?”

Baba said, “We are poor. We are a large family which depends only on my job. My parents died when I was about three years old. My uncle took everything—the farm, house and even me. Uncle wanted me to work on the farm but I wanted an education, so one day I ran away from my village to Mumbai to study. I lived in a hostel, studying for my SSC exams and found myself on the merit list. My teachers wanted me to study further but I had to support myself. During those days I was fascinated by the uniform that the police wore, so smart and elegant they looked. So, as soon as I got my results I wanted to apply for the police force. Seeing my grades, one of the officers advised me to study further. But when he saw that I was adamant, he advised me to go to the Central Excise Department instead of the police department. And so I came to be employed as an Inspector in the Central Excise. I was infamous in the village because I’d run away, but when I got the job I still went to visit uncle. Before I knew it, he got me married. I never knew then that the house in which he lived, the farm which he tilled and on which his family was dependent was rightfully mine and should have come back to me. Anyway...coming back to the present...I think my family lives happily if not luxuriously on my salary. What do you think? I haven’t visited our village for many years, but you can go if you wish to.”

I never did, but both my brothers went. All they got from Baba’s uncle were some old copper and bronze pots,

some glassware and fresh mangoes. When uncle’s son came to stay with us later for a few years for his studies Baba received him with open arms. How could such a large-hearted father ever be poor? And that’s how I came to be upset each time if someone ever called me “poor” even for fun.

When Rehana and I quarreled, Baba always took Rehana’s side and Ma took mine. When Baba was cross with Ma, she took it out on me and beat me though I hadn’t done anything wrong. Rehana was only one and a half years older than I and could easily wear my clothes. When I left for school a bit early to play, Rehana wore my clothes which I’d carefully washed and ironed. I got mad with her. But since it wasn’t right to quarrel in front of others, I used to keep quiet while she used to smile smugly to herself. But when we came home, all hell broke loose and I vented my anger by turning on her. Ironically, years later, when I became disabled, Rehana managed everything—her studies, job, cooking, cleaning the house. She even ironed my clothes and kept them near my bed, handy, though I told her I didn’t need ironed clothes since I never went out.

Today, when I look back, I wonder how I could have beaten such a sister for wearing my clothes. Once I said to her, “Rinna (we all called her Rinna) look, you wore my ironed clothes once in a while, so see how God punished you big time—now you wash and iron my clothes *everyday*!”

To which she said, “Nachchu, (I was called Nachchu) if it were possible to share your disability we could have done it in turns. I would be in your wheelchair for a few days and you would have been ironing all the clothes!”

As children we shared the daily household chores—sweeping and mopping the floor, making beds, washing clothes and utensils, folding dry clothes and stacking them away in respective cupboards, lighting the boiler, making tea, kneading dough for chapattis, storing water and so on. Ma’s sense of discipline then now stands me in good stead as I manage the running of our hostel. We would, very often, compare our own work with Ma’s and Baba’s. Oh yes, Baba did a lot of housework—he used to cook and stitch on holidays and I can say with pride that we never employed anyone for washing and cleaning.



On Sundays, as soon as we woke up, we worked in the garden with Ma and Baba. The kitchen was out of bounds for Ma on Sundays. So we pitched in with Baba and it turned out that the food would taste much better than usual because the best ingredients were used in shameless abundance. Ingredients which Ma would have spread out sparingly over four days, Baba used up in a single day! But no one complained. And best of all, we usually had snacks instead of a proper dinner. On Sunday afternoons, we all played Rummy or Hukum with Ma and Baba.

I remember an incident when I was in school at Nanded. Our school was near a fort. Often, Rehana's friend used to walk with us. They loved to scout for new paths and short cuts.

"Hey, you'd better shut up about this or we'll leave you out of our adventures. What's more, you'll have to walk alone!" they threatened me. I was only in class three and I was terrified of walking alone.

"Walk alone?" I bleated, horrified. "No, no, I won't tell anyone, promise," I said, pinching my throat. These explorations took place on Saturday afternoons and though I was thrilled to be included, it was exhausting for me to walk on an empty stomach.

One day, as we were passing through a lane, a young boy clutched at Rehana's friend's hand and said, "Come with me, I'll show you a *new way*." Perhaps we never really knew what he meant but still we young girls were aghast. Sensing danger, we pushed him aside and ran as fast as we could! That was the end of looking for "new paths." Rehana never brought up the subject again. But now...ah that's a different story. I'm forever looking for new ways and short cuts as I conduct the affairs of our institution, Helpers of the Handicapped. And have very nearly achieved mastery over the art of doing so.

I can never forget two incidents which took place in Jaisingpur when I was in class five and six respectively. It was a co-ed school. Now it so happened that one of the teachers punished some boys in a particular class. So some troublemaker boys in the school decided that the teacher should be boycotted and no one should attend his class. The cheek of it—a handful of boys ordering everyone else, and worse, several cowardly ones

actually obeying! I refused to budge, saying, "I'm going to stay and attend his class. My parents would be furious if they knew that I'd bunked class and was wandering around. Who're these boys anyway to upset our class and insult the teacher?"

My friends told me, "Naseem, don't be stubborn, those boys are dangerous."

"Let's see what they do. I haven't hassled anyone, why would they hassle me?" I asked.

My friends must have loved me for they stayed back with me. But as luck would have it, the teacher didn't turn up. We waited and waited but he never came.

So we decided to go and see the floods on the rail bridge. We had to cross over to our sewing class and since we were early, we walked along leisurely, chatting away. We didn't have watches then, so it was easy to lose track of time. The water lapped dangerously on either side of the railway line, so we had little place to stand except on the tracks themselves. And then we heard the train. The bridge stretched endlessly in front of us. "Run!" we shouted to each other. I thought of the races I'd run and won, but this was hardly the time to compete. We all had to make it or we'd be mowed down by the train. God was certainly with us for we never ran so fast. Just as our feet touched the other end of the rail bridge, on the edge of the tracks, the train hurtled past us. Panting and puffing, we looked at each other. Were we really alive? I went weak with relief as I saw Rehana running towards me, shaking like a leaf. Holding me tight, she asked, "Naseem, child, are you hurt? What happened?" Someone had told her about her sister and the flooded rail bridge.

"Oh Rinna, don't tell Ma please!" I begged and sobbed. "I've kept your secrets too, haven't I?"

"Yes, don't worry," she said. From that day Rehana was not just my sister but also my friend.

The other incident concerns a certain dance event. Once, earlier in Nanded, I'd danced as the colour blue, one of the seven colours of the rainbow. We won the prize. Later, while I was in school in Jaisingpur, a dance competition was announced. I volunteered and got selected. I was bursting with joy and wanted to share the news at home. I was then in class seven.

"Ma, I'm going to dance," I said happily.



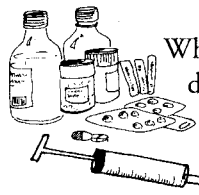


"No you're not. You're not so young any more. You'll do no such thing," she said firmly.

Nothing worked, not all my howling and crying. So I told my teacher, "I can't dance. My folks won't let me."

"Hmmm...well...let me try. I'll talk to your parents and get their permission," he told me.

I don't know what he did, but he convinced Ma to let me dance. I was to be Radha in a Radha-Krishna dance. The song went somewhat like this—"Murali ki dhun sun Radha bole..." There was a rhythm too—"dhet dhet, tirakita dhet, dhit dhit kata dha kita, takita, ta na ta tita kata, gadhi gana dha." A commentary went with it which I've forgotten now. I loved coordinating my steps with the rhythm. In fact, I loved every bit of the dancing—moving the neck, the facial expressions and bending my body, bow-like. I loved dancing! The two sisters who played the roles of Krishna and Yashoda took classical dance lessons. With no such training, I was embarrassed to practice with them but they egged me on. In fact, they even suggested that I should also learn classical dance. I knew how difficult that would be. I knew that my parents would never allow it, considering that they'd even stopped my elder sister's schooling in class seven because she was "grown up." In our Muslim community dancing is a no-no for women. But how could I tell my friends all this?



When dawn peeped in through my window the next day, I was all agog and alert. It was the day of the function where I was to dance and I trembled with excitement. Not able to contain myself beyond breakfast, I went first to my closest friend, Ranjana Tavdare's house to go with her to school early. Just as we were leaving, Ranjana's elder brother said, "Hmmm, I'd like to see who's going to dance today!" Turning to me he said, "Oh, perhaps it's...you?" The sarcasm in his voice was unmistakable. "Have you seen the stage on which you're supposed to dance? It's going to collapse! It's very unlikely you'll be able to finish," he continued, as my face fell.



He was always making fun of us girls, so I became defiant, "What's the bet, you'll see! You'll eat your words!" Thus saying we marched off, Ranjana and I, hand in hand.

The curtain went up as I appeared on the stage. I saw Baba with his friends in the very first row. Baba! I was more overjoyed at seeing him there than at the opportunity I got to dance. Getting a nod of appreciation from ones own folks was a thousand times more precious than praise from others. I began to dance with all my heart...only Krishna was there... only Krishna. My skirts swung and my hair flew, I was dancing with all my devotion. All of a sudden I heard a loud noise... *kadad kadad kad!* And, in an instant, I was dangling head down along with the carpet which was spread on the stage. I could see nothing but the bottom of the rather crude wooden platform with the jagged ends of a few planks jutting out rudely. As I lifted my head in a daze, vaguely recalling Ranjana's brother's words, Baba and several others were trying to lift me up. I noticed that the curtain had come down.

In a jiffy the collapsed planks were joined together again and the stage was up almost immediately. Some young men jumped up and down on the planks just to make sure they were securely fastened.

"Naseem, are you hurt?" I heard voices.

"No." Just then I heard a voice on the mike, it was a call for the *next* item. How dare they...I was furious!

"Come on, this isn't fair!" I protested. "Why should we be left out of the competition when it's not even *our* fault?"

Angrily, I marched up to our teacher and told him "Sir, what's this? We *must* complete our dance! It's not our fault that our dance should be dismissed from the competition."

He was surprised, "What? Will you dance *again*?"

"Yes," I said and Krishna held my hand tight.

So we got our chance and we danced again. The applause was thunderous and they were still clapping when we came to sit among the audience. We bagged the first prize, but I couldn't help wondering why. Did they want to please Baba who was upset that his daughter fell through the stage or because we were determined to finish despite the fall or because our performance was the best? I'll never know. After that episode, despite all the fuss and tears, I was never allowed to dance, so



I've never been able to judge for myself how or where I stood with respect to dance. Even today, when I watch dances in the movies or television, or see Sudha Chandran—a dancer who lost one of her legs in an accident but got fitted with an artificial limb and continued to dance—that's when I wish I had a little sensation in my legs, at least for a brief while so I could dance a bit. At the very least, I wish I could tap my feet to the rhythm of music. That's when I most regret that I have no photograph of my dance performances.

From Jaisingpur we moved to Kolhapur. Rehana and I went to a girls' school near our house. Rehana was acting in a play called *Usana Navara* (The Borrowed Husband) in which she had to wear a nine-yard sari. But, unlike in my case earlier, no teacher had to come home to seek permission from my parents. Like an advocate she argued for her own case, "Naseem was allowed to dance *twice*. This is only a play. I *will* take part."

Emboldened by this, I organised a one-act play the next year and performed it at one of the smaller school functions. I chose the play myself and was its Director. Almost prophetically, it was titled "*Mookam Karoti Vachalam, Pangum Langhayate Girim*," which meant, "The Mute can Talk and the Disabled can Climb a Mountain." Mr Jeevan Kamble was our headmaster and our source of inspiration. I think he must have liked it, because, not only did he give us a pat on our backs, but also asked us to re-perform it at a larger function—our annual day celebrations. We were proud and happy, but Padma Shirodkar, a fellow actor, made a complete mess.

Here's what happened. A certain episode had some humorous lines. Padma had to say them, but even before she could say the first word, she burst into a fit of uncontrollable laughter. She couldn't stop laughing. Chandu and I, who were on the stage with her, tried to normalise the situation.

"Look, what's there to laugh about?" We made it seem like another line in the play.

Chandu went closer to Padma and said, "Look, you'd better control your laughter!" By now Padma was hysterical, more so on hearing lines that were not in the script. A roar of laughter swelled up from the audience who now sensed that a serious play had turned into a silly comedy. The curtain fell. We couldn't continue because Padma's laughter had turned into racking sobs.

"I've spoilt everything for you!" she wailed. She refused to be consoled and we finally gave up, play and all.

Many years later, when Padma met me for the first time after I became disabled, she was assailed by the same racking sobs. She was simple but intelligent, and though she was two years my junior, we were good friends. Her father, now quite old, helps me a great deal with my work at Helpers. On his birthday one year, he told his friends and relations to pass on to Helpers all the gifts that they were planning to give him. We got many cheques and demand drafts. At that point I couldn't help but recall how Kamble Sir had told us to grow vegetables in our schoolyard and offer up the sale of these vegetables to the school kitty.

Two incidents from my school days at Kolhapur are clearly etched in my memory. Sanskrit was never a part of my school syllabus in Jaisingpur. But I'd learnt how to sew. So, in my first quarterly exam at Kolhapur, I got five marks out of a hundred in Sanskrit and ninety in sewing. Rehana, on the other hand, got more than ninety in Sanskrit and five in sewing. The Sanskrit teacher made fun of me in front of the whole class, saying, "Naseema, learn from your sister. She's so clever that she stands first in her class." Since then I nursed a silent grudge against that teacher. I did, however, learn Sanskrit from Rehana and pushed my marks up to about sixty.

The Sanskrit teacher wore a cap every day of the year. As always, on Diwali day he wore a new one. It seemed that he never washed it throughout the year, for as the days progressed, the cap acquired layer after layer of oil and dirt. One question foxed all of us. How did he look *without* his cap? Did he have hair or was he bald?

Once, on the first of April, he was facing the blackboard scribbling something in the Devnagari script. I don't know what came over me, but suddenly I cried, "Sir, there's a big caterpillar on your cap!" Off came the cap and with a thwack, he flung it on the table, his eyes round with horror. And there it was, on his pate, the little black beauty—a neatly tied up tuft on his smoothly shaven head! So he did have nice hair after all which he kept shaved because of the community that he came from.



"Where's the insect?" he shouted.

"April Fool, Sir!" my friends and I shouted louder than the others.

He was fair like Rehana, so when he turned a bright shade of red it was more than visible. Menacingly, he held out his stick and we put out our hands silently. But he wasn't satisfied with the caning.

"Go, get the headmaster's permission to sit in my class," he thundered, wagging his stick in agitation.

We pleaded, "Sir, it was only an April Fool's joke, why make an issue of it? We won't play these tricks with our teachers and elders ever again! Please forgive us." The humility in our voices should do the trick, we thought. He cleared his throat and began on his favourite Sanskrit student, "Now...let's take Rehana, she wouldn't do something like this....why can't you all learn from her?"

Some of us yawned, "Oh no, not again!" we groaned.

In Kamble Sir's office we told him, mustering up all our innocence, "We didn't know that we couldn't play April Fool jokes on our teachers. Forgive us, we'll never do it again."

Kamble Sir just smiled and asked us to go back to class! Just like that, no punishment! We must have been his favourites.

On our way back home that day, I told Rehana and her friends about the Sanskrit teacher, the cap and the caterpillar and how sporting Kamble Sir was. They laughed till the tears streamed down their faces. But the travails of the Sanskrit teacher were not to end so fast. It turned out that his "favourite" Rehana too would have a hand in this.

He was busy teaching her class. Rehana and her friend came in late and told him that Kamble Sir wanted him in his office for some work. He put the chalk down and strode off looking rather important. No sooner had he gone than he came back and the class screamed, "April Fool!" because Kamble Sir had not called him.

No caning this time, no chucking anyone out. Instead he merely smiled. It was Rehana after all, his best and brightest student.

In our old school in Jaisingpur, Physical Training meant that we had to do a few exercises. But here, in Kolhapur, we had to march. I couldn't move my arms and legs in

coordination and before long I was thrown out of the march past much to my discomfiture. But the PT teacher was very nice and told me how to move properly. I'm going to get it right, I decided. For eight days I practiced....*left-right, left-right*. It must have worked for not only was I selected but was also allowed to give orders to the march past contingent! In fact, I was judged the best marcher.

Then began the pain in my back.

I was in class nine then. My doctors forbade me from playing any games—kho-kho, kabaddi, throwball or any form of physical training. They gave the school a medical certificate that would excuse me.

With every passing day, the pain became unbearable. It was exam time, but I couldn't study. Kamble Sir told me, "Tell your illness to wait a little. Tell it that you have no time to pay attention to it or pamper it and that you'll take care of it after the exams."

I went through my exams in a cloud of acute pain. I still remember all the medicines, fomentations and injections. I had no option but to take to my bed where I lay in dire pain for two months. I couldn't bear the slightest touch on my body or sleep straight on my bed for a single night, sometimes spending entire nights sitting in an easy chair or on the bed propped up with cushions. Ma and Baba were by my side constantly. But I didn't need anything except sleep. My complexion turned dark. Even combing my curly hair made me wince and scream with pain and so most of the time my hair was left uncombed. During this miserable time, Kamble Sir used to visit me often.

Another thing I remember clearly during this period was the tingling sensation that I felt waist down every now and then. The retinue of doctors starting with Dr Jadhav pumped me with injections and gave me electric fomentations on my back. In a couple of months I began to feel better.

I told every doctor who treated me, "When I take a bath I can feel the heat of the water on the upper part of my body but lower down, I can't make out whether it's hot or cold." I wasn't to know then how ominous this would turn out to be.

My father spent all the money he possibly could. When a particular medicine was not effective the half-used bottle was shelved and a new one bought. During those days, there was always a heap of half used medicines.



My grades came crashing down. Either it was because of my illness or maybe because the other students were smarter, I'll never know. But from number two or three I slipped down to four or five. Rehana, though, never missed her first rank but I managed a second rank just once. I took my class eleven Secondary School Certificate (SSC) exams in the middle of all that excruciating pain. That was probably why I missed a first division and it made me very unhappy but I consoled myself that I even managed to pass at all. Almost immediately I was bedridden again. Something new started happening, my body began to convulse. During my holidays I went to stay with my maternal grandparents, though I had to spend the entire time in bed.

Rehana finished her schooling a year before me. There was no shortage of advice from "well wishers" which finally convinced Ma. They said, "Don't send her to college. She'll get spoilt and it'll be difficult to get her married." My sister Jaibun, older to Rehana, had studied only up to class seven which posed a problem when they were looking for a groom for her. She wasn't educated enough they said. So Baba allowed Rehana to attend college. Rehana wanted to be a doctor and so did I. But my illness coupled with my poor SSC marks came in the way. At least a nurse, if not a doctor, I'd hoped. Sensing that my physical deterioration was slow but sure, my doctors advised me not to take up Science Major (it was more demanding) so I finally joined Humanities in Rajaram College.

My youngest sister Kausar was in class one then and brother Aziz in eight. We all wanted Kausar to go to an English medium school. But we couldn't afford to put her in a convent school, so she went to the same school as Rehana and myself. She was the youngest of all of us and everyone's pet, particularly Baba's. "Don't scold her, just explain things to her," he would say. When I was ill, Ma and Baba used to sleep near me in turns. When Baba was with me she went to Ma and if Ma was near me she went to Baba.

Soon I grew up. My childhood was over and I was in my youth, the most exciting time in life or so everyone said. At the same time I often wished that I were still a child. If I were the youngest, like Kausar, everyone would pamper me. On

the other hand it would be great to be the oldest and command my siblings. Still, I bid goodbye to childhood with its world of memories and entered the colourful world of college. The first day...

I was very apprehensive. Rehana had told me about the boys and their teasing ways. For the past four years I was in a girl's school and didn't quite know how to deal with boys or sit with them together in class. In those days, in 1966, it was quite uncommon for girls to wear a salwar-kameez. However, I was bold enough to wear one on my first day at college.

Rajaram College was located in the Bhavani Mantap Palace. I entered with a bunch of my schoolmates, Usha, Shobha and Aruna in tow. The boys were everywhere. One of them, holding a big rose came towards us, saying, "*Ba adab ba mulhija hoshiyar, malika padhar rahi hai*," which meant, "attention please, the queen is arriving!"

Ma's instructions were clear. We were to keep our eyes down and not respond to any such comments. The boys could then make whatever judgments they wanted to and very likely, would leave us alone. But if we dared to argue or retort angrily, it would only serve to encourage those good for nothing louts. So that's what we did. We didn't dare look up and went straight to class. But there were only girl students there busy getting introduced to each other.

Usha Dafale with the nice handwriting was my closest friend. She introduced me to the others saying, "Friends, this is Naseem, uh...hmmm...a scholar par excellence." What a strange introduction, I thought to myself. Was this a direct and sarcastic pointer to the first division I'd missed? I was really miffed with her.

I said, "Usha has a habit of making sarcastic remarks like this."

Later we had a big row. She insisted that she hadn't meant to tease me and thought I was intelligent, really. Well, I said, if that was so, how come I got such poor marks? Though we were just a street apart, we didn't talk to each other for a year. We even took different routes to avoid meeting each other. And since we took different courses in college, we rarely met.

Within a month I had many friends. Since Rehana had opted for Science and I for Humanities, she never knew what



I was up to and couldn't report anything at home. In those days we could opt to join either the National Cadet Corps (NCC) or Physical Training. I was told by my doctors to avoid any form of physical exercise. Joining the NCC, therefore, would have been a dead giveaway because of the uniform. I opted for PT instead, so I could satisfy my craving for sports but ignoring the doctor's advice completely. Not only did I flout doctors' orders, but I stood for elections for the post of PT leader and surprisingly got the maximum number of votes. In fact, at the end of the year, I won the prize for best PT leader. That certificate, even now, gives me the greatest joy. Leadership gives one confidence.

Once, after my PT session, I was skipping with a rope when suddenly I felt an excruciating pain in my back. I blacked out. I can't remember whether I sat down or fell flat but when I opened my eyes I saw light. Someone had poured water on my face and I found a glass of water near me. As soon as I could muster some strength, I told my friends, between sips of water, not to report this incident to my parents or Rehana if they wanted to see me on the playground again. They didn't know then what grim destiny lay in store for me.

And then I saw that my feet had lost their coordination. "Seems like you're enamoured by the boys. You walk so stylishly," my friends pulled my legs. Then I noticed that it wasn't just the feet, I couldn't control my bladder either. If my parents knew, they'd have immediately stopped my education. Exams were round the corner and I didn't want to be uneducated like Jaibun Aapa, so I kept quiet. But my old problem, which was under check for the last eight months, was now raising its painful head again. I still remember what happened about ten days before I was bedridden again.

Rehana and I had a row about something silly. Ma, in a fit of anger about our constant bickering, raised her hand to hit me, but before she laid her hand on me, I sat down, overcome by an unbearable shooting pain in my back. Ma thought I was faking just to avoid a beating. She gave me a sound thrashing anyway. I could neither stand up nor utter a word because of the pain and anger. But Rehana saw the expression on my face and noticed that my movements had become awkward. I don't know what was going on in her

mind at that moment, but all she did was pick me up and put me on a bed. I didn't know then that that bed would be mine forever. Tears of agony flowed uncontrollably and I bit my lips to bear the pain. At that point, Rehana knew something was seriously wrong and begged to be forgiven. Ma too must have sensed something because she asked me what the matter was and I told her that I wouldn't be attending college because of back pain. As soon as she heard "back pain" her voice became gentle. She gave me some milk and medicines. I lay down, silent, hurting like hell, thinking, sinking into a well of misery. I casually put my hand under my pillow and came up with a storybook, probably hidden there by Rehana. But the words swam like a blur in front of my eyes as I thought again and again, "How could Ma possibly think that I was faking the pain?" I sobbed myself to sleep.

I remember another incident. I was in class six, studying for my approaching exams. It was evening and Baba had bought a nice big fish for dinner. Ma was grinding spices for the curry and my sister was frying the fish. Just then the kerosene in the stove ran out and Ma asked me to refill it. I made a face because I had to leave my books. It was a practice at home to cook special dishes when our exams were near in order to entice us to eat despite the tension that often killed our appetites. My sister was putting fish into the hot oil as I was filling the stove. Some of the boiling oil splashed and fell on the back of my right hand, between the wrist and fingers. I screamed. Ma thought I was making too much of a fuss for a minor burn and scolded me, but as usual, Rehana was spared for splashing the oil on me in the first place. I finished filling the kerosene though my hand hurt really badly. I quietly went to the bathroom, poured some water on my hand and let my tears flow silently. It was impossible for me to get back to my books, in fact, I was wondering whether I'd be able to write my exam the next day. I sat in a dark corner and when I was called for dinner I said I wasn't hungry. I couldn't have eaten with my hand the way it was and I didn't want anyone to see it either.

But Ma sent Rehana again to call me. When she saw my hand, Rehana's jaw dropped. She called everyone to see it. By now there was a blister almost the size of a puri. I was suddenly



the object of a lot of fuss. A tube of Burnol came from somewhere and the ointment was rubbed over my hand. Ma handfed me that day and for many days applied a paste of burnt coconut so that there wouldn't be any scar. It took several days for the burn to heal.

"Naseem, how on earth could you be so calm even when your hand was so badly burnt?" I was asked again and again by everyone in the family.

As the days passed, I'd forgotten this incident but Rehana often reminds me about it to this day. What I didn't know then was that this was perhaps destiny's way of making me rehearse for what was in store for me—pain hundred times worse than this.

My meals started coming to my bed as my backache worsened. One day, just as I was getting ready for a post lunch nap, I had a vivid recollection of a particular incident. I was lying on this very bed reading a book of Rehana's. She asked me for the book and I refused. She tried to snatch it from me. I was lying on my back and she started to tickle me, hoping to get at the book. I was laughing and moving and soon I found my head dangling over the edge of the bed. Half of me was on the bed while the other half dangled over the edge. I held the book fast and the tickling made me choke with laughter. Actually, I was suffocating but Rehana thought I was laughing. But she must have sensed something not quite normal, for she pulled me up immediately and lay me down properly.

When my breathing became normal she asked me if I was hurt and I pointed to my back. I recall her applying some ointment. Then, as usual, in a conspiratorial tone, she asked me not to report this to anyone. No, of course not, I nodded. After all, we had so many secrets between us. Besides, I knew Rehana hadn't done anything with the intention of hurting me. Soon the pain vanished and I forgot all about it.

I remember how the doctors kept asking me as I went through diagnostic tests one after the other, "Did you ever fall somewhere and hurt your back? How did it all start?" I'd never mentioned the tickling incident on the bed fearing that Rehana could get into trouble. But who really knows how it started? Could it be my fall from the school stage, or my

kabaddi games when I fell flat on my back several times or even the tickling episode? Later, after the operation, I got to know that the same Rehana who swore me to secrecy had confessed everything to Baba in a flood of tears.

Though I was completely bedridden by now, Ma, Baba and Kamble Sir felt that I should get admitted to the Wanless hospital in Miraj. My exams were round the corner and since I'd studied well, I insisted on taking them before going to the hospital. This time round the pain was much more acute. It was becoming impossible to go to the toilet. I was swelling all over and my skin had turned black. I was bombarded with medicines, injections and fomentations, but there was no improvement. My parents were so desperate that when someone told them to apply ground fenugreek on my back, they promptly did so. What can I say? I thought it was better to die. I still remember my screams as the coat dried and it was removed.

I was in a state of drowsy sedation most of the time. Once, while I was fast asleep, I felt my legs being pinned down by a strong pair of hands. They were so heavy, as if they were made of stone or iron, and when I tried to raise them to touch the mosquito net around my bed, I just couldn't. Something or someone was pushing my shoulders and chest down with all its might.

"Who's it? Drive it away!" I cried aloud.

My grandmother, Aaji, was visiting us because I was ill. She was near my bed and she said, "Naseem, there's no one, it's just a bad dream."

But I was fully awake, it was not a dream. No one believed me. Anyway, Aaji blew out some air from her mouth as if to drive away an evil spirit. Then she prayed over me. "Don't go," I pleaded, "it will get me again!" She sat with me for a while longer.

The exams began. First I would go in an auto-rickshaw to the doctor for an injection and fomentation and then proceed to the hall. I managed to write two papers. On the day of the third paper, a friend who had no idea about my illness, came up from behind and gently put her hand on my shoulder. I screamed. Soon there was a small crowd and my poor friend, afraid of what she'd done, was almost in tears. The pain was



unbearable and I somehow staggered into the classroom. I was in a daze and couldn't remember a word of what I'd studied. Just then I heard a song being played from a distance. I scribbled down the words of the songs on my answer sheet. Back home when Bhaijaan asked me how I'd fared, I began to weep. I told them what I did.

Baba said, "It's better to give in a blank paper than scribble songs or draw rangolis."

How I managed to write the subsequent papers and get a second division in all the subjects that year is still a miracle to me.

For a whole year my friends had been urging me to join them for a movie or go to eat ice creams. I never did, fearing that my folks would disapprove. That I was allowed to study was more than enough for me. But after my last exam paper, I decided that I would go out with my friends. We planned to go for the three o'clock matinee show. Surprisingly, my parents agreed. But the last paper left me so exhausted that I couldn't even sit, so my friends wanted to cancel the matinee and take me to a doctor instead. I said no, we *will* see the film. The name of the film was *Yeh Zindagi Kitni Haseen Hai!* —*How Beautiful Life Is!* Normally, I would have been able to identify Dilip Kumar and Meena Kumari, the glamorous star pair. On that particular day, I couldn't care whether life was beautiful or not or even follow the story line leave alone identify the cast. All I knew was the pain. Three long hours I sat through the show because I didn't want to spoil the afternoon for my friends.

Aruna and I returned home together. At a certain point we had to take separate paths to our houses and I had to walk a small stretch alone. It was getting dark so I told Aruna that she need not walk me home.

Aruna Kamat was an intelligent girl but very quiet by nature. Her father was an officer in the Life Insurance Corporation and he had a company car, an Ambassador. He would take both of us to college in his car everyday. Even if Aruna was absent he would still come to fetch me. I rarely missed classes but Aruna often used to stay back at home because of some ill health. Many people in the college thought that Mr Kamat was *my* father. Aruna and I normally took a

bus to return home, though I got off at the halfway bus station and walked the remaining distance to Tarabai Park. This way I could save half the money from the bus ticket. I added this saving to my pocket money and bought myself a nice pink salwar-kameez. It had pretty, light-coloured machine embroidery on it. I was wearing this dress on the day we went for the movie.

As I was walking alone towards home I came face to face with a group of buffaloes. It was dark already. I was terrified at the prospect of being gored by the horns of one of them, but I just couldn't walk fast enough because of the pain. I began to sweat. Home was really a very short distance away, but how could I get there when I couldn't even lift my foot! Oh God, why did I send Aruna home! I should've asked her to escort me. Will someone from home come looking for me? I sat and then stood, not knowing what to do. I don't know when and how I reached the front steps of my house. I collapsed in a heap on one of them, unable to budge. I had no idea who found me there and when I was rushed to the Mary Wanless Hospital near Kawla Naka.

I got admitted and spent six days going through X-rays and other tests. They couldn't find anything wrong with the reports. So Dr Bidri declared, "This girl is being pampered too much!" Since I hardly had an appetite, my family used to bring a variety of dishes from home to lure me to eat. That's probably why Dr Bidri said that. But most often, the food remained untouched because of the pain. Sometimes it got so bad that I screamed loud enough for people to hear me on the road outside. Even the tiniest movement of my body was excruciating. But since the X-rays didn't show up anything, Dr Bidri forced me to get up from my bed. I was trembling like a leaf, but he ordered me to move my foot. As soon as I did that I started collapsing. Not letting me go, he held my arm and tried to haul me up. I started bellowing like a beast. Other patients began to gather around me. Is this doctor human or is he a demon, they began to murmur.

"There's nothing wrong with her, it's just a college love affair. Her disease is psychological," the good doctor pronounced. He didn't stop there. He advised Baba to take me to a psychiatrist!

It was April 24, a day I remember only too well. I tried walking to the toilet, one step at a time, supported by my mother and sister, screaming all the time. But just outside the door I collapsed. When I opened my eyes, I don't know how many hours later, I found myself in a special room, not in the ward. I couldn't feel anything below the waist and a urine bag was attached to the bed. The pain had subsided completely but I could move only my hands.

Dr Bidri would not give me permission to leave the hospital though I had no sensation in the lower part of my body. Baba was furious and threatened to register a case against the hospital. Fearing adverse publicity, they gave us the hospital ambulance along with a doctor and a nurse, and I was taken to the Wanless Hospital in Miraj.

Today, even recalling all this in order to write this book, I feel an uneasy stress. I remember my days at the Wanless Hospital where I went through heaps and heaps of pain and made pathetic efforts to cure myself. As I delve into my past I feel a stab of pain in my spine and a cold and clammy sensation creeping down my arms. My hands are ice cold and I feel a tingling sensation at intervals. I can't move my fingers. Familiar with and mortally afraid of this tingling sensation, I went to Dr Mohanrao Gune and sobbed bitterly. I had felt the same tingling in my legs before the lower part of my body packed up.

In Miraj, I went through a mylogram. It's a process where they inject a coloured fluid into the spine and take an X-ray immediately thereafter. They found that one of the vertebrae was pressed and there was a cyst on the spinal cord. It was to be removed immediately. This was during the days of Dr Donaldson and Dr Pradhan and they were to do the operation. On 20 May 1967, as I was being wheeled into the operation theatre, I was confident that once the cyst was removed, I would get back my waist-down sensation in the same way that water would flow down a pipe if an existing blockage was removed. After the operation I would be able to stand, walk and feel. Wearing an armour of these happy thoughts I was ready to face the chloroform. I couldn't for the life of me understand why Ma, Baba, my uncle, Aaji, and my brothers and sisters looked so worried. I'd even decided that once I got better I would do a nursing course

in this very hospital at Miraj. My motivation was especially a young girl named Sanjeevani.

Sanjeevani's uncle got her married. She was on her way to her in-laws' place and on the way she met with an accident. Her condition was similar to mine—no sensation waist down. Eventually she became a paraplegic. Nobody ever came to visit her, neither her husband nor her in-laws. She had no one in her own family. She was in the hospital for eleven months coping with not just her disability but being an orphan as well. Some people gave her clothes, others food. How awful she must have felt—I used to shudder at the thought.

As they wheeled me out on the stretcher from the operation theatre, I came to. I noticed the blood on my sheets as they transferred me to my bed. There was a seven-inch long incision on my spine with thirteen stitches. Such was the pain when I tried to change sides that I just wanted to die. Rather than live with the pain, I asked for poison. I lay like that for a whole month. But I felt no sense of touch returning to my lower body.

One day Ma was changing my sheets. Suddenly she screamed and I noticed that she was trembling all over. What could be the matter, I didn't see anything. But Ma had found a group of ants under my bottom. The lower half of my body had been eaten by ants and it looked like a newly grooved grinding stone with blood all over. And while all this was going on, I couldn't feel anything! Ma cried so much that her eyes were swollen. She cried all night. She couldn't bear to even step into the room imagining how I must have suffered. She began to clean my bed more often now and as she did she kept looking at my legs waiting for the slightest movement. One day she thought she detected a slight movement in my big toe. She was so thrilled that she told everyone. The worst was over, she said. But one day, the doctors got me a wheelchair and I was lifted into it. I was sitting up after several months, so my head drooped and I felt dizzy and I was put back on the bed again. Even this much exertion was too much for me and I broke into cold sweat. The next day I was back in the wheelchair. This time I felt better, especially because I was out in the sun and fresh air. The doctor himself showed me how to operate the wheelchair—how to go straight and turn



right, how to keep the right hand steady and manoeuvre with my left hand, the iron ring near the big wheel to the right. I couldn't stand up but I could at least go out into the fresh air in my wheelchair. I was wheeled to the physiotherapy center managed by Shyam and Kishore, two wonderful people, for my exercises. As they worked on me they kept chatting so I didn't feel bored.

One day, they advised my parents to take me to a rehabilitation centre. Rehabilitation centre? What kind of place is that? Ma and Baba thought they were suggesting that I should be sent to "this place" permanently so that I wouldn't be a burden on them. "We'll manage everything ourselves at home," they snapped back, hurt at the suggestion. They didn't even bother to note down the address of the centre.

I had two big bedsores on my bottom. Every time I took the ultra violet ray treatment I was repulsed and disgusted by my own body. But my hopes of getting better and my wish to keep my parents happy kept me laughing and going.

I was discharged from the hospital in this condition. Little did I know that I was to proceed to a death chamber. It was located in Belambar, a tiny village in Karnataka. We took a taxi from Miraj and on the way we stopped for a few minutes at Kolhapur to collect some of our things. I started crying. Baba looked at me with a little irritation. How could I tell him that I was upset because I'd come to look upon the wheelchair as a friend and now I was discharged from the hospital without one?

It was a small dark room without any ventilation. There was one door to the room and then just a wall on the other side. Not a single window. All five of us—Ma, Baba, Aaji, Uncle and I—spent a whole month at Belambar. The treatment was to be administered in the dark without a trace of sunlight. I was being massaged with herbal oils morning and evening and given a hot bath afterwards. Only men were allowed to do this because it was believed that women should not handle these herbs and oils. To me this was complete torture and I called it "Kalapani," the punishment treatment. I am amazed, to this day, how we spent a whole month in that dark, dank room on the earthen floor, all five of us, in the damp rainy season.

But the good thing was that the two bedsores dried up during this time. Even as I went through those "torture" massages, I began to feel, with more conviction everyday, that I too, like Sanjeevani, had become permanently disabled. I couldn't deal with my mental anguish, though my physical pain had reduced. I would cry the whole day.

One day Baba lost his temper. He said, "Naseem, your crying makes everyone else cry. It makes the whole family unhappy. Can't you see how badly your mother is affected? If crying could cure our miseries and calamities, we could cry all day." I knew all of them were crying secretly. He continued, "Try to smile and lighten up the atmosphere a little. Let's laugh and make others laugh, we could all do with a little more strength."

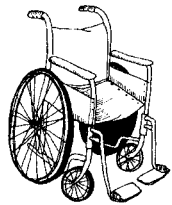
I was shocked to see how angry Baba was but I indulged in a little self-pity, crying, "How can he shout at me when I'm going through all this!" I was very unhappy but I made a sullen resolution. If my weeping was making others miserable, I wouldn't do it in front of them. And from that day onwards, I never cry in front of others. After all, I have the whole night to myself, I thought. After Baba's outburst I stopped crying and took a good look at my parents. They had lost so much weight and looked weary and gaunt. It was all my fault. Baba even stopped smoking to cut costs.

From the death chamber at Belambar we went to Kumta to Aaji's place. The vaid or traditional doctor at Belambar had prescribed hot water baths. I was made to sit on a stool and two people would help me go through the ordeal. After the bath, Ma would lay me down on my stomach and sprinkle powder all over my back. One day, as she was doing this, she found big burn blisters caused by the scalding water, on my bottom. From waist downwards I was totally burnt and I had felt nothing! Ma started crying, saying, "How could I have burnt my little girl like this?" A doctor was called immediately. He cleaned all the blisters, applied medicine and gave me an injection. I still had fever. Since then, Ma always poured the hot water over her own hand before letting it flow on to me.

I will never forget the ants and these burns. Because of the raw wounds, I had to keep lying on my tummy. But I didn't complain or Ma would have blamed herself even more.

Baba had taken leave from work for five months because of my illness. Now he had to report back for work. To add to our woes, Baba was transferred to Aurangabad. Usually the whole family would go wherever Baba was posted, but now because of me that wasn't possible. Finally it was decided that Ma and I would live in Kumta with my grandparents and my brothers and sisters would continue living in Kolhapur for their education under the care of my aunt, Badrunnissa who would shift there. But Ma and Baba had to go to Kolhapur at least once before Baba could pack off for Aurangabad. Because of my constant fever, Ma didn't want to leave me alone in Kumta but I insisted, saying, "Go help Baba pack properly. Everyone here takes care of me as lovingly as you do."

Baba was to go to Aurangabad alone. Ma was to go to Kolhapur to help Baba with the packing then come back to Kumta. Till then I was to be looked after by my sister, aunt and Aaji.



No one told me but by now I knew that I had become a paraplegic. Do you know what it feels like to be a paraplegic? As a small girl, I had read a story about a king who had been cursed by someone. Half his body turned to stone, rendering him immobile, pinning him down in a particular place for years. Then someone came and removed the curse and he became a whole man again. Half *my* body, from the waist to the tips of my toes had turned to stone. The only difference was that the king in the story was standing whereas I had to lie down all the while. Half my body was going to be listless for the rest of my life. I had no control over my urine or bowels, neither was I aware of when I passed them. When there was an odour I was turned on my side and the sheets would be changed. It required four people to do this. Powder, perfume and even incense sticks were used to keep the odour at bay. The radio was switched on to cheer me up and a storybook kept next to me. But the tears flowed and kept wetting my pillow. Only a sleeping pill would finally put an end to my tears.



I was sixteen and begging Allah Miyan to give me death. My death would also free those who love me. Either that or my legs should be restored to me I bargained. At the very least, give me enough strength to manage my own toilette needs so that Ma was not troubled. I'd heard that God punished people in strange ways for doing bad things. But what wrong did I do? I'd never harmed anyone in school or during the one year in college. I'd always been happy helping others. I'd shared my books and notes with anyone who needed them. At Aaji's place, I washed utensils and clothes, carried water from the well, cleaned the courtyard and strung mogra garlands. And I enjoyed their affection in return. So why me? I just couldn't understand.

In Kolhapur we lived in a rented house. During my illness, for the first time, we missed paying the rent on time for a month or two. The landlord began to feel that we might settle there permanently because of my disability and was after us to vacate. Finally, we rented another house in Tarabai Park. Ma and Baba were in Kumta with me. Patil Kaka was a friend of Baba's and with his help, my brothers and sisters shifted to the new rented place. The latches of the front and back doors in this new place opened with the slightest push. It was not very secure but there wasn't anything in the house worth stealing. Our savings were exhausted and Ma mortgaged the little jewellery she had. But the new landlord, Mr Kelavkar was so kind that he never asked us for the rent even if it was due for months. We lived there for about thirteen years at the end of which we were told by friends that we would never have to shift since we could legally claim the house as ours. But Ma said that we would never be happy grabbing someone else's property and that was that.

Thus my aunt and my siblings stayed in the new house. On September 1, Baba went to Aurangabad and Ma came back to Kumta. He wrote saying that he had rented a room and a peon from his office lived with him. When he wrote to Ma, he wrote to me too. That was the first letter I ever received from Baba because he had never stayed away from us before. It was in English but since I was not used to his handwriting, my uncle read it out to me, "Be happy and





keep smiling. This tragedy will blow over. Take care of your mother." The letter was full of affection. I read it many times and then wrote back. He replied to Ma, "Naseem has written a very good letter. I like her style of writing. Tell her that I will reply when I have some time." I was waiting for my reply.

On September 23, Ma went downstairs after giving me a bath. It was eleven in the morning. She was back in my room almost immediately. She looked pale and I can't remember who it was, but someone was holding her. Mama held a telegram in her hand.

"Ma, what is it?" I asked her, going pale myself.

"It says 'Father serious'," Ma gasped.

"But...when...how?" I asked, suspecting that something terrible had happened.

We got a telephone call informing us that Baba was being taken to Kolhapur from Aurangabad and we should reach there.

We called for a taxi. I was hoisted in and Ma sat by my side. Neither of us spoke a word. As we negotiated the distance from Kumta to Kolhapur, I heard Ma's choking sobs at intervals. I took her hand in mine every now and then. They were icy cold. The journey seemed unending. Finally we reached Tarabai Park at one o'clock at night. From the Central Excise office to our new house, I saw several people standing on both sides of the road in the quiet hours of the night in white clothes. The slightest hope I had of seeing Baba alive vanished. But I didn't cry, I had become a rock. I could only remember Baba's words, "Your miseries won't end by crying."

I was taken into the house I had never seen. Baba's body, wrapped in a white sheet, with cotton in his nostrils, lay in the big hall. I was seeing a dead body for the first time and that had to be Baba's. As I took it all in, my eyes were lifeless. Ma was hysterical, "You've gone without telling me, leaving me alone. How will I bring up five children?"

The body couldn't be kept like this for very much longer. So within ten minutes they lifted Baba and brought his body to where I lay and I touched his forehead. Suddenly, I remembered how Baba had kissed me on the forehead when I was writhing in pain in the hospital in Miraj and

expressed his inability to share my agony. That affectionate touch had subdued my pain for a while. Soon, Baba's body was taken away.

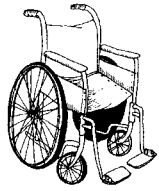
That day we received two telegrams within an hour—one about Baba's death and the other about Rehana's admission to medical college.

From the very next day, we heard stories. When Baba was in Kolhapur, a colleague of his got suspended. He wanted Baba to give false evidence in his case and save him from suspension. Baba couldn't have lied and been unfaithful to his organisation even for a friend. And since Baba told the truth, his friend got suspended. This colleague had now moved to Aurangabad.

Baba was used to working late hours in the office. Even on that fateful last day, he was working late when this friend dropped in. He insisted that they go out and get a cup of tea. Though Baba wasn't in the mood, he agreed. When the friend left, he began to feel nauseous. So he took a rickshaw back home and asked the peon for some lemon juice. Sitting at the dining table he took a sip. He must have felt very sick because he told the peon to fetch a doctor. The fellow ran out but by the time he came back, Baba had died.

Not knowing who he could turn to, the peon went to the colleague who appeared with a doctor. Later we came to know that he used all his influence to avoid a post mortem and brought Baba's body intact to Kolhapur in a special taxi. Everybody at home was grateful to him and praised him for his unstinting help. But I was not happy with the whole affair. An ordinary doctor had diagnosed a cardiac arrest and issued a certificate. Why wasn't a post mortem done? This was a sudden, unexpected death after all. Why was everyone keeping quiet? But I was only sixteen and not bold enough to voice my doubts. To top it all, the gold ring on Baba's hand was missing. After asking around, we got to know that a certain peon had sold it to a goldsmith in Aurangabad. We had evidence against him, but Ma said, "Let it be. We've lost someone who was more precious than gold. What will we do with a gold ring? Besides, the man is poor. We must think of his wife and children."

Ma had forgiven him even before he asked for it. I am proud we have such a mother.



We had to face one tragedy after another. Baba died on 23 September 1967. I was now completely bedridden. In December 1967, we witnessed our first earthquake. It was the month of Ramadan and we were up early to break our fast. It was still dark outside.

Suddenly a series of tremors ripped through the earth, making the walls shake. Instead of running out to save themselves, the whole family gathered around my bed. Ma was calm. She said, "Allah is speaking to us. Pray!" I was frightened beyond words, but almost glad that if I died in the earthquake, I would be free of this hellish business of living the life of a paraplegic. But the thundering and quaking stopped and an hour later, there were smaller tremors.

At daybreak, the earthquake was the topic of conversation everywhere. We heard horrible stories of how the quake took its toll on families in Koyana. Our uncle, who was in Goa, came to Kolhapur immediately as did Patil Kaka. We gave him a graphic account of what happened the previous night. Uncle heard us out, his face clouding over.

"Okay, so there was an earthquake. But what you did, or rather, *didn't* do is downright foolish!" he said. "What on earth were you trying to accomplish by huddling inside the house? Did you think death was certain? What if you didn't die, but suffered some terrible injury that only made you disabled? Would you like that? Haven't you been reading the newspaper articles on how we should protect ourselves from earthquakes? The answer is to rush out, not stay indoors."

So when the tremors shook the house again, Rehana, Aziz, and Ma wanted to carry my bed outside. But I said, "Just leave me alone, you're wasting time. Why don't you let me die? I'm already disabled and bedridden. Just save yourselves." Naturally no one listened; they moved my bed to the outer room, closer to the outside. On another occasion, we heard an announcement that there would be tremors from eight in the evening. Rehana assigned jobs to everyone. If the house caved in we would have to rush out. For this our footwear had to be kept handy. So we put all our footwear in a basket near the door. One set of clothes for each person was put in a bag. She got together some stuff for cooking, and gathered leftover food like rotis. A basket with some vegetables was kept handy.



Ma put money in a small pouch and tied it to her waist. At the very first tremor I was taken outside and laid on a mattress on the bare ground. I had no wheelchair. It was December and very cold. The dew made everything wet so an umbrella was put over my head. That was my first experience of nomadic life out in the open.

Aunt Badrunissa and I were the most affected during this time. Our heartbeats would race and we couldn't eat. Besides, I was beginning to get irritated at all the fuss over me. I thought, "Why can't they stop trying to save me? They're inviting disaster for themselves!"

One day, Ma tried to knock some sense into my aunt and myself saying, "Why don't you accept the reality of the situation? It's your own fuss and whimsy that'll make you ill, not the earthquake. Pray instead and repeat the name of Allah." This outburst made us quiet but we still couldn't sleep. What if a scampering rat made us sit up and cry "earthquake!" Wouldn't it be embarrassing? And that's exactly what happened once. A rat did scamper and the whole household woke up in the middle of the night screaming earthquake. They even managed to carry me out of the house in a jiffy. But Bhaijaan was most annoyed and ordered us to go back to sleep. There is no need to stay awake for a mouse he said. Despite the tension we laughed. Over time, I got over my fear of earthquakes.

And then there was the assortment of dreams. I dreamt that I was sitting on a small, wheeled platform by the roadside, the type that disabled beggars used while begging. People, seeing how badly off I was, were throwing some money at me. I would wake up in cold sweat. Gradually this dream stopped. Then there was the other one. I was flying in the sky, flying through valleys, forests and rivers. Yet another dream was one that I often had as a child but was now recurring. I was wandering about in a huge mansion by the seaside. It's a mansion I know well. I am familiar with the gate, the steps, the rooms, the black rocks outside and the waves splashing against them. I still dream of that house and my flight through the valleys and mountains. I loved these night dreams and what's more, I was happy daydreaming about them. In my daydreams I was in college and winning prizes in dance and sports competitions.



Doing all the cooking at home and getting a pat from Ma was another dream. Sometimes I would see myself going to college in a wheelchair. Then I would be in a big office. Everyone looked at me admiringly. With my salary I got clothes and sweets for everyone at home. Even as I was dreaming up all this I knew how impossible it all was and how I would be a mere burden on my family. But today, at fifty, I know that if you have a dream and work hard towards it, nothing is impossible!

Aziz, my younger brother was very naughty but Yusuf, the older one was quiet. When we had a row, Aziz had the habit of pulling Rehana's and my hair. There were complaints about him from school too and this worried Ma and Baba. But when I became seriously ill and Baba died, Aziz suddenly changed. The naughty little boy started growing into a confident young man—he was doing things with more confidence than Rehana, myself or even Bhaijaan. After Baba's death, Rehana took up a job but it couldn't sustain the family. So Ma decided to breed hens and sell the eggs. Aziz promptly fetched bamboo poles on his bicycle and made a shelter for the chickens. He was only in class eight but contributed to the household kitty by selling the eggs and vegetables that Ma had grown.

Since my childhood days, I secretly nurtured an inferiority complex which could have become monstrous after I became physically disabled had it not been for the tremendous encouragement and support from my family. Dirty or clean, easy or difficult as the task may have been, they rolled up their sleeves at the drop of a hat and never made me feel neglected. In fact, they were always suggesting how something could be managed better. From the bed into the wheelchair, from the wheelchair into a rickshaw, they would do it first and then tell me to do it myself.

My uncle, Haroon Khan was with me throughout my treatment at Miraj and later during my "death chamber" experience at Belambar. He had shelved his business responsibilities to be with his family. He was married to Jamila Aapajan, my second sister and my older uncle was married to my eldest sister Suraiyya Behenjaan. Aapajaan still nurses me like Ma used to do. In Kumta, my aunt Raheela, who was somewhat my own age, lived with my grandparents. I am

grateful to many members of my family for their nursing care, but to Aapajan and Raheela in particular. They played cards with me and took me out to the movies. Ma sent me money from Kolhapur just so that I could go to see them.

Uncle Haroon's business became bankrupt, so he couldn't send much money to my grandmother. But despite that, I was amazed to see how she entertained guests and took special care of my food, all with a smiling face. I couldn't eat coarse boiled rice so I got expensive rice. There were no rotis for the others but I got rotis and milk. I felt embarrassed and awkward, and kept praying that my grandparents would see better times.

I spent six months in Kumta with Raheela, doing mostly embroidery and knitting. Now I was getting a little browned off and felt like going back to Kolhapur. I was homesick and missed my family terribly but then I would console myself thinking that as long as I was in Kumta, Ma didn't have to carry me, give me a bath and wash my sheets. But then in Kumta, my grandparents were going through lean times. Either way I was a burden and this fact would agitate me no end and make me toss and turn at night. I wished everyday that I was dead. Anyhow, now I was firm about going back to Kolhapur.

After Baba's death, the family was to get some money. When it came finally, Ma bought me a wheelchair. The Rotary and Lions Clubs offered to give me a free wheelchair, but it didn't do much for my self-respect and I refused it. We sent the wheelchair company the full payment but they failed to send it and so we sent them a legal notice. Finally, after much waiting, it arrived in Kolhapur while I was still in Kumta and it was despatched to me immediately.

A wheelchair at last! What freedom from this constant lying down on a bed! I would move around and feel like a normal human being once more and not like a sack of potatoes! Ma and Aziz came to fetch me from Kumta and take me back to Kolhapur. They couldn't afford a taxi so they took a state transport bus and we were returning by bus too. As I was being wheeled to the bus, people stared at me. A couple of them nudged their way through the crowd and came up to me. They wanted to know how I came to be this way. When I



told them my story, they clucked sympathetically, "Poor girl, so young and see what she has to go through! A curse for the whole family, no doubt! Must be the sins of a previous birth, what else?" I was already apprehensive about doing this twelve-hour journey by bus in my condition and on top of that I had to hear this kind of talk. Fortunately my bedsores and wounds had healed and we also had reserved seats on the bus. That day, when I took leave of everyone at Kumta, their eyes were moist and mine brimmed over with tears.

I thought how difficult it must be for Uncle Haroon, Aziz and Ma to do the same tiresome journey again twice over. Uncle has no fingers on his right hand, only a wrist. As a child, a comb he was holding caught fire and he lost his fingers. But this didn't stop him from doing just about anything including lifting me up each time. The bus station was crowded as usual. We made our way through the crowd and my wheelchair was now near the bus. Aziz was pushing away people to make way for Uncle who carried me in his arms. He clambered in with me. To our surprise, some people were sitting in our reserved seats. We requested them to move, but they refused to budge. Uncle's hands were aching with my weight so I was transferred to Aziz. He tried explaining to them in Kannada about my condition and the need for us to sit down urgently. Why did we have to explain anyway, those were *our* seats! Poor Aziz, little as he was, carried me as if he was holding a child. The pushing and shoving grew worse as more people jostled into the bus. Uncle was afraid that I might slip down from Aziz's hands any moment and so he literally tried to pull up the man who was sitting on our seat and asked Aziz to put me down. Just then about six people attacked Uncle and beat him up so badly that he had blood all over his face. It was brutal, inhuman and unbelievable! Aziz tried to intervene but the row continued. The bus conductor had no choice but to take the vehicle to the police station. Finally we got our seats and the bus set off. The melee and fighting set us back by a good two hours, so the journey became longer. I was aghast and dumbfounded by this kind of abject human behaviour. Can humans be so inhuman? I didn't cry then, but since all this had happened because of me, I took a resolution, then and there, not to travel hereafter. I couldn't do this to anyone.

At last we reached Kolhapur.

My brothers and sisters were busy with their studies and household work. I was bored and lonely. How long could one read books or listen to the radio? One day, my old friend, Usha Dafale, with whom I had a skirmish some time ago and Shaku Rupe, another friend, came to see me. We got chatting and time just flew. Just as they were about to leave, Usha said, "Naseem, I must tell you something. I came to see you so many times, but turned away from your door without meeting you because of that argument on the first day of college. I was afraid you might think that I'd come to just tease you and make you unhappy. But each time I turned away, I went back very upset. I'm so glad that we met today and all is well. Is it okay if I come everyday?" From that day, till she got married, she came home each evening as did my other friends, Shaku, Aruna, Hema and Alka. Those evening sessions were so happy and chatty, sometimes going on till eight in the night. They got me books and supplied me with college news. I guess they didn't quite realise that I could feel bad because I couldn't go to college.

Sometimes misunderstandings occur because of our own perceptions about things. For instance, after Baba's death, no one would mention him at home. If we saw one of his favourite dishes on the table, we would eat it without uttering a word, but we would all be thinking about him. One day Ma and I were alone at home. I told her about a dream that I had. In the dream Baba was alive. He was kidnapped, but after many years, managed to free himself and return home. Our house was in the forest, the same mansion that I would dream about so often. We were all thrilled to see him back. Ma was cooking for him excitedly. You see, after Baba's death, Ma hadn't entered the kitchen for several months. But in the dream it was different.

Suddenly Ma lifted her hand to stop me, "Baba, Baba...I'm surprised that you even *dream* of him. None of you ever *think* about your father. You never mention him at all!"

I said, "No Ma, you're wrong. We miss Baba every moment. But we don't talk about him when you're around thinking it might hurt you."

I saw how we had one set of perceptions and Ma another. I seized the opportunity then to tell her that I believed that the cause of Baba's death was not natural.

It might be pertinent here, to explain the nature of his job. Baba worked with the Central Excise and Customs Department and it was part of his job to apprehend smuggled goods and other contraband. Baba was responsible for registering many cases and therefore had many enemies.

I remember one Diwali day. Firecrackers rent the air as we sat on our verandah chatting. It was getting dark when suddenly there was a hail of stones. We rushed indoors and shut the main door. The stones rained down still. Then it stopped. Baba hadn't as yet returned from office, but as soon as he did, we told him what happened. It was dinner time but we could hardly eat because we were so scared. But the food was ready and we sat down. The stones came again, pelting on the tiled roof of the kitchen. Baba rose to investigate, but we stopped him. It was too dangerous. Just as we were about to turn in, there was another terrifying shower. By now, we were petrified and huddled together in a room. The exams were near and we had to study. But that was impossible under the circumstances. We kept awake for a long time after that, and then dropped off one by one.

The next day, for another eight days, we got some peons from Baba's office to keep a secret watch in the evenings. Nothing happened. Then, as the vigil slackened a bit, the stones rained down on us, this time, even more furiously. From the way the stones hit the roof, it was clear that they were thrown from a house nearby or even from the branch of a neighbouring tree. Our window had a ledge, so unless someone came really close, there was no way that the stones could come in through the window grills. The vigil became more alert.

Once, while I was still attending school, Baba returned very late at night. He was still asleep early in the morning as I sat studying in his room with my back towards him. His bed, which had a mosquito net around it, was near a window. Suddenly a shadow fell on my table and my breath drew in sharp. I saw a man near the window! Should I call someone or disturb Baba? I rose as silently as I could, my heart in my mouth. Then through the window came the stones fast and furious.

Baba woke up and though I ran through the back door as fast as I could, the man had crossed the open field and disappeared.

Those days I went to the civil hospital every day to take an injection for my back pain. A peon from Baba's office accompanied me. On that particular day, near the compound wall of my school, I saw a man who looked just like the man I had seen near Baba's window. He passed by with a small sickle in his hand.

"Wait a minute," I told the peon "I seem to recognise him." I took a good long look at him. When we returned I found the man lingering at the same place.

"Let's go home quickly and tell Baba," I told the peon. But he did something really strange—he walked up to the lurking man and told him that I suspected him! The man laughed, said something and walked away hurriedly.

That night it happened again. The peons, hiding in the bushes, tried to catch the man but he fled. Ma, and especially us girls, actually felt relieved that he managed to escape, for if he were caught, he would have been thrashed within an inch of his life. In all likelihood, he was merely a hired hand trying to make a few bucks for his family. Someone else was clearly behind this.

Over the years, we have had to face many such challenging situations, which I believe, must have shaped my character and personality. Let's say they trained me to keep my cool in trying circumstances. This training stands me in good stead today as I try to manage our institution, Helpers of the Handicapped. When I see people panic, I find I can stay calm. I believe, now more than ever, that every problem gives us an opportunity to learn and solving it takes us a step forward in life. I'm not easily fazed by problems, especially because I have the faith that God has a plan and will help me along.

I always remember Baba's words which he often repeated, "*Khudhi ko kar buland itna ki har taqdeer se pehle khuda bande se khud pooche, beta teri raza kya hai?*" It meant—"Make yourself so strong that God himself will ask you, 'Son, what is your wish?'" But how could I ever become so strong? I would sit in the courtyard and gaze at the stars till late at night thinking, thinking. It was during this time that Aruna's father became "my Baba." He would take me out in his car to eat out. My friends, brothers and sisters would take me to the movies and

to the park. Going out in the sun, breathing the fresh air, mingling with crowds in public places—these are blessings you will count when you have been doing nothing but staring at the beams on the ceiling for a whole year.

It was 1970. One day, Aruna's father took me to meet Babu Kaka Diwan at Rama Kaki's house. Rama Kaki was a blind woman. Babu Kaka arrived in an imported red car and I noticed that he was at the wheel. The car stopped in front of the house and out came a wheelchair. Babu Kaka had a pleasant smile as he wheeled himself towards me. I don't remember exactly what he said, but I do remember being overwhelmed at seeing a man on a wheelchair smile so happily and talk about things like big industry and air travel. I had a strange feeling that I had indeed found my *buland* man in Baba's *khudi ko kar buland* poem! He told me how I should complete my education and participate in sports competitions for the disabled. He also told me that I should not only get self-reliant but help other disabled people in Kolhapur. It was a day I could never forget because for the first time I felt I had control over my own disability. And as I sat listening to him I almost forgot that I was in a wheelchair. I read the book, *Manoos Motha Jiddicha (Such a Determined Fellow)*, based on Babu Kaka's life. What impressed me most then was a photograph of Babu Kaka with Prime Minister Jawaharlal Nehru whose good wishes were written in his own hand!

Despite everyone's objections, Rehana left college and began to learn shorthand and typing. She took various exams for jobs. She got calls from both the Income Tax and Central Excise offices at the same time.

Ma was most upset and declared, "I will not make my daughter work and live on *her* income!"

But Uncle Haroon and Patil Kaka pointed out to her that our situation was bad and we had little choice. So Rehana went to work and continued her studies from home. She passed her BA exams with good marks. Rehana knew that I wanted to study though I hadn't said so to her, so she sent a letter to the university on my behalf. The reply came saying that only those who were married, had jobs or lived outside Maharashtra could appear externally for the exams. Clearly, disability was not an issue and I was refused.

I told Babu Kaka about this. He said that I should waste no time in meeting M R Desai, Principal of Gokhale College. M R's daughter, Leena had been my classmate. Aruna sent her a message and M R himself came to meet me. He asked Aziz to go back with him and sent me all the books I needed from the book bank. I had met Babu Kaka at Diwali and twenty days later I met M R. I had just two and a half months to prepare for the exams. I'd lost three years, but M R said, "We have marked you present from June onwards. Study well."

I wasn't sure if I could pull this off but I started studying. I read the books and made notes. I didn't have to sit in the courtyard at night and gaze at the stars anymore. I could sleep.

The exams terrified me. Nightmares haunted me every night. They repeated themselves relentlessly. I was going to the exam hall in a taxi. And horror of horrors, the wheelchair got left behind at home. In the taxi I kept asking Aziz, or a friend or one of my sisters who accompanied me, whether the wheelchair was in the trunk of the car. And most frightening of all, I dreamt I had to write some of my papers seated on the floor and others on the upper floors!

I made it to the hall on time. And then as I got busy writing, the supervisor edged up to me, looked pointedly at my wheelchair and asked me personal questions—when did it happen, how, and so on. I didn't mind the questions but couldn't he figure out that the timing was most inappropriate? Finally, I couldn't take it anymore. The barrage of questions continued. I had to put my foot down and say, "Please, is it okay if I told you my entire tale after the paper?"

I wrote all my papers but was most unsure of how I would fare. Fortunately, I passed in all the subjects including English.

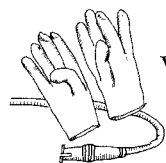
I was touched by Babu Kaka's congratulatory letter. Congratulations poured in from my friends and family and spurred me to continue studying. The next year, I studied at leisure for a whole year and luckily got a seat in Gokhale College. All the professors, including M R himself, took great care of me and pampered me by giving me tea and snacks at break time. I passed my BA with honours and was thrilled. On Convocation Day, I wanted myself photographed in the convocation gown just like my classmates but felt too shy to say it. I don't know what got

into me, but for some reason I couldn't get myself to even attend the convocation ceremony.

Once Ma was away from Kolhapur. Rehana, who was just a year and a half older than I, managed everything—her job, the cooking, and even giving me a bath. Aziz, helped her with the dishes. And Kausar, who was eight years younger than I, did the other chores like cleaning, making beds and so on. I was the only one who did nothing and I had more free time than all the others. One day, I told Aziz that I'd had enough of lounging around and watching them work. I too wanted to be of some use to the household. How about cooking? No sooner said than he wheeled me into the kitchen. On a stove which was kept on a low stool, I made poha, a dish of spicy flattened rice, while he kept passing me the ingredients. When Rehana returned from office, we ate it and everyone said, "Mmmm...delicious!"

The very next day, Aziz, Rehana and Kausar changed the layout of the kitchen to accommodate my newfound cooking talents. They brought down the raw materials from the upper wall-racks and placed them within my reach. I sat in my wheelchair and started making rotis, vegetables, rice and curry. Finally I was of some use and able to shoulder a part of the household responsibility. I could even wash the dishes.

I had just given my BA exams when I read about a writing competition in *Swarajya*, a weekly periodical, on *Sutttil Upakrama (The Holiday Project)*. I thought why not? The subject I chose was my new experience of cooking in a wheelchair. I sent it in and, wonder of wonders, one day Rehana came home waving the published article! We celebrated with hot snacks and tea.



We were so busy negotiating the several travails that assailed our family that none of us sensed that little Kausar was being neglected by all of us after Baba's death. What's worse, we were unconsciously using her as a punching bag to vent our frustrations. Consequently, our bubbly, smiling Kausar became serious and quiet. One day a teacher from her school told us that Kausar had got a

scholarship. That was some revelation! Now it so happened that she'd saved up from this scholarship money to buy herself a red frock. Once, when Ma was away from Kolhapur, some unexpected guests dropped in and none of us had any money. So we had to resort to Kausar's money which she gave with a smile. A few days later Ma returned. One day, while preparing her school bag, she stumbled on a poem about a red frock. That's how we all knew. Dear, brave Kausar. When Rehana got her next month's salary she bought a red frock and gave it to a surprised but delighted Kausar.

If there's one thing that I'm grateful for, it's my family. They have risen to every conceivable occasion as far as I was concerned. For instance, they fixed a handle on a foot-pedal sewing machine so I spent a lot of time stitching. When my brother took up a job abroad later, he installed a motor on the same machine, making it easier for me to sew. They were forever trying to convert my sorrows to joy. On my part, I learnt to combat the sorrows by persevering all the more.

Babu Kaka visited Kolhapur, the place of his birth, once every two years. Whenever he came he would call together all the disabled people he knew and organise meetings. He urged us to work for the rehabilitation of other disabled people. It was most exciting to travel in his hand-controlled car and to hear his speeches. Those were happy days. For the first time, I began to think about *other* disabled people, little realising till then that there were so many of us even in my own town, people who were far worse off than me. One day, I woke up with a resolution to work for them like Babu Kaka. On one of his trips to Kolhapur in 1972, we drew up plans for an institution and named it Apang Punarvasan Sanstha (Centre for the Rehabilitation of the Disabled). But first, he invited me to Bangalore to see his own institution there. Shri Datta Bal, a well-known personality of Kolhapur, footed my travel expenses.

But how would I travel? I had no control over my bladder or bowels. So I was padded with cloth from bed sheets whenever I went out. With Babu Kaka's help, we made a slight improvement on this arrangement. Two bed sheets with a plastic sheet in between were kept in a square cushion cover. When one side got soiled, the other side was turned up. But this arrangement was temporary and would last only for my

shorter trips within Kolhapur. The long journey to Bangalore was another story altogether. So I used a simple catheter, but unfortunately, it slipped out in the train. I was quite distraught but Raheela and Aziz, who accompanied me, asked me to be patient. Surely, Babu Kaka would find a way out.

I had to take laxatives regularly, but they were not very effective, so I had to have enemas. The enemas gave me a reaction and I broke out in patches. I had to be taken twice to the hospital for this problem.

In Bangalore, Babu Kaka looked after me like his own daughter. He took me to his clinic where they fitted me with a new Foley's Catheter. This was in 1972. And as if by some magic, I stopped soiling my clothes. I was so thrilled that I even took part in a sports competition for the disabled and became a champion! I danced with my other disabled friends who had come from different places. Me, playing and dancing! Me, whose eyes used to fill up if I heard someone merely *mention* sports or dancing.

However, in that crowd of disabled people, I noticed that there was no other woman like myself who had lost all sensation waist down and suffered from incontinence and uncontrolled bowels. But there were men, jawans from the army, who were in the same condition as I was. Many years later, in 1996, when an organisation in Mumbai invited me to talk on "How a Paraplegic Woman Should Live," I agreed to speak without any hesitation.

In Bangalore, we tried to assess the number of women who were to be in the rehabilitation programme. We found that most of them were polio victims, unlike me who had lost all sensation, and who dared to leave her home and participate in a sports competition. Why was that? Lack of training and social stigmas were the reasons I realised. I want to make a special mention of this, because I know of a paraplegic woman, who, twenty-six years ago, was written off by society and imprisoned within the four walls of her home. She's still there and this must change, I thought.

As I write this, two paraplegic women from the villages come to my mind—Anita Rane, uneducated, full of sores, lying on a piece of sacking on a wooden divan to prevent her from soiling mattresses and doing crochet covers, and Susheela,

a graduate, lying on a length of sacking on the floor. I tried my best to bring them to Kolhapur to get them to be self-reliant but got no cooperation from their parents.

In Bangalore, I lived in Babu Kaka's care for twelve days and nights. I watched how meaningfully he lived and my life changed altogether. I have never loved, respected or worshipped anyone else as I did Babu Kaka. Even today, I love Babu Kaka most of all. He explained to me how to wear surgical hand gloves in the left hand and clear out my bowels. Quite complicated in the beginning, I soon learnt to tackle this singular problem which made me want to die all the time. Now, as soon as I woke up every morning, I could clear my stomach voluntarily, so that there was no tension of soiling my clothes if I was working or went out during the day. I could therefore concentrate on work and studies. When I was leaving Bangalore, Babu Kaka gave me a lovely sari. He came to the station to see me off and I saw his moist eyes and thought how lonely he must be. I should live in Bangalore like his daughter and cook for him, take care of him. He toils for others morning till night yet his food comes from outside. When we were together in Bangalore, we used to cook breakfast in our room and share it with him. We were given a room adjacent to the workshop near his own room so I spent a great deal of time in Babu Kaka's office and saw the work he was doing. He told me to start similar work in Kolhapur, but I didn't think I was at all capable.

All the while I had a nagging thought—Babu Kaka taught me to overcome the most common difficulties faced by us paraplegics, yet why are patients discharged from hospitals not taught the most elementary things? Even today, I request many doctors to teach and train patients before sending them home, or fortunately, since we have facilities in Helpers, to send them to us for training.

On my way back from Bangalore I kept recalling certain episodes from the sports meet. A rather dandy and somewhat rakish young man showed me how to throw the discus, shotput and javelin as well as how to play table tennis on a wheelchair. He became my guru for that period of time. One night, as we all sat singing and talking to players from Belgaum and Baroda, the subject of a certain stylish young man with a disability



came up. It was past ten but he hadn't returned. It turned out that he'd gone out with a beautiful, disabled girl from Belgaum. She used crutches. I was a bit shocked.

"How could she be out with that rake at this hour?" I asked her teammates.

They said, "Oh well, he's taken her to meet his aunt. If she approves of her he will meet the girl's mother in Belgaum. We thought why should we dampen the chances of a disabled girl getting married? So we let her go alone."

I told Babu Kaka the next day, when he had some free time, "Do you know that Meena is getting married?"

"To whom?" Babu Kaka's expression was incredulous.

"To Ashok, why?" I asked.

"Ashok? That chap? But he has a wife and daughter!"

Babu Kaka asked me to write to the girl's family in Belgaum and inform them immediately. But I was already two days late—by then the guy had already visited her home, enjoyed the hospitality of the family and disappeared without a word. The girl, a decent and good-hearted sort, had fallen in love with him and her heart was broken. The bright young thing became a recluse for some time and then all of a sudden, started going out with several men one after the other with a vengeance. In the end she married a much older man with children. She had withered before she could blossom.

After Bangalore, I went to Mumbai in 1973 for the Paraplegic Foundation sports meet. And guess who I met there but Ashok, the Rake! I discovered something interesting. Etibar Khan, Rehana's husband, whom I call Bhaisaab happened, once, to see him putting on his clothes after a swim.

Bhaisaab asked me, "Don't paraplegic men put their trousers on by pulling them up with their hands? But, Naseem, I clearly saw this man put his legs in first like we do! What kind of paraplegic does that?"

It so happened that I managed to catch Ashok alone once.

"So Ashok, what about Meena, where's she now?" I asked.

If he was surprised he managed to disguise it. He shrugged his shoulders and said casually, "Well, I tried to get her married to my friend, but he didn't approve of her."

"But why didn't you tell her that you were already married?" I pushed.

"How was I to know that they weren't aware of it?" he replied, much to my anger. Obviously he was not conscience-stricken.

"Creep," I thought to myself.

Babu Kaka came to the Mumbai meet. He introduced me to several people. The Mumbai team was used to shaking hands with people, but I preferred the traditional Indian greeting of joining hands and saying "namaste."

"Being precious, are you?" they jibed. I was teased on account of this and acquired a nickname, "Lavangi Mirchi" (Hot Little Chilly).

I was a star in Mumbai, standing first and winning several medals for javelin throwing, wheelchair race, shotput, discus and table tennis. I received my shield and medals, one by one, the applause thundering and echoing around me. I was truly overwhelmed. I was happier still because Aziz, Rehana, Bhaisaab and Babu Kaka were also clapping madly.

Back in Kolhapur, I received a letter saying that I had been chosen for the International Stoke Mandville Games in England. I couldn't believe my luck! In my dreams, I often saw myself flying in an aircraft and sitting next to the pilot in the cockpit. Now I was actually going to sit...no fly....in an aircraft for seventeen hours! My dreams were becoming real! I told Babu Kaka about it. Soon after, I got a letter from the Secretary of the Paraplegic Foundation saying that he was coming to Kolhapur to raise funds for my trip to England.

I found this strange. *They* had chosen me, invited me and now they wanted to collect money from my own town! I'd just completed my graduation and was in the process of setting up an institution for rehabilitation of the disabled. I was also planning a vocational training center. All this would require a lot of money and land. How could I, at a time like this, raise money for my personal expenses to attend a sports meet when I would have to tap the same sources for a public cause later? Earlier, Babu Kaka had said that it was okay to take money from Datta Bal for the Bangalore meet. He'd said then, "We need to start *somewhere* to begin our own rehabilitation and progress, so sometimes we need to take money from others. But tomorrow we should return it with interest." But still, I wasn't comfortable with the idea of collecting money for myself



from Kolhapur. I wrote to Babu Kaka about how I felt. He replied promptly, "You're right. Those who selected you should bear the expenses. Write to them about it. At the same time, make sure you go to Mumbai to attend the meeting of the National Society for Equal Opportunities for the Handicapped (NASEOH) for which you will be getting an invitation. Mr Vijay Merchant is the President. You must discuss the matter of your expenses with him. I'm sure something can be worked out."

"Mr Vijay Merchant himself!" I thought excitedly. I was to meet the great cricketer in person. At the NASEOH meeting, Babu Kaka introduced me as I wheeled myself in. Vijay Bhai got up from his seat at the other end of the room and came over to greet me. He took my hands in his and kissed me on my forehead. I was reminded of Baba.

I couldn't speak in English, but my Hindi was good enough to discuss the issue with him. The decision came finally. NASEOH would pay the expenses for three competitors, two women and one man to go to England. The Secretary of the Paraplegic Foundation was accordingly informed on the phone.

Instead of going straight to Khar, a suburb in Mumbai, to visit Rehana, who now lived there, I went with Babu Kaka and Nama Bhat, Secretary of NASEOH, to meet Fatima Ismail, founder of Fellowship of the Physically Handicapped, at her residence. I was so glad that I went—I learnt so much that day, both through conversations on the way and from Ms Ismail herself.

Fatima Ismail has a disabled daughter, Usha, who now lives in New York. In the course of our conversation, Fatima shared some anecdotes from Usha's childhood with us.

Here's one such story. Fatima was in the habit of pressurising her daughter to do well in her studies. She was determined that Usha should be well educated and independent despite her disability. One day, when Fatima was particularly angry with Usha for not studying, she gave her a sound scolding. Usha's maid, hearing all this said, "Why do you put so much pressure on the poor girl? Isn't it enough that she's trying to cope with her disability? In addition, she has to cope with your scolding."

Fatima's eyes filled up. She thought, "The maid is right. Usha has no contact with the outside world unlike other children who go out and play. My daughter's life is limited to these four walls, going through endless treatments and massages. Still I'm after her, study....study! She needs much more love, that's what she needs."

Wiping her eyes, Fatima got up to go to another room. It was then that she heard Usha ticking off the maid.

"Why did you say that to Amma?" Usha was saying. "Now look, she's crying because of your stupid remarks. What do you know? Amma shouts at me for my own good. She's not my enemy! Don't talk like this ever again!"

Perhaps disabled children mature early in life. Fatima was moved beyond words. She had a catch in her throat as she hugged her daughter with all her heart. Wiping away her mother's tears, Usha said, "Amma, I'll never make you cry again. I'll work really hard from now on." And she opened her book.

Fatima told us many such stories. Nama Tai, on her part, recalled a particular experience. Once she took in a pretty beggar girl from the streets and admitted her in an orphanage. Nama Tai would go there once in a while to enquire about her. The girl was intelligent but loth to study. She wasn't very clean either, and if some one rebuked her, she would behave even worse than before. There were no rules in her life or love for that matter. Nama Tai had observed that some of the boys teased her. Since she'd grown to like this orphan girl, she felt very protective about her. So every so often she took her aside and told her how to behave. The "good" behaviour lasted for a few days and then she was back to her old ways. She was rude and gave lip to the authorities. Once it so happened that she was punished for some mischief by the orphanage authorities. She threw a massive tantrum and picked up her things to leave.

"I don't want to live in this ashram anymore! It's just bondage, nothing else! It's easier for me to sing a couple of songs on the street and feed myself!" she screamed.

The superintendent called Nama Tai. The girl was very difficult to handle and she didn't want to be responsible for her anymore. She just wouldn't brook any form of discipline. Nama Tai tried to be patient. Suddenly there was an outburst from the girl, "Who are you anyway? And why are you after me like this?"

Nama Tai was furious. She slapped her hard and said, "Get lost! How will you ever know the meaning of love? You seem to enjoy the greedy stare of the street. Go! Obviously you don't understand the difference between the life of a street beggar and a respectable life!"

Before Nama Tai could finish, the girl was at her feet begging for mercy, crying, "Please forgive me! It's because no one ever loved me. But you'll see, I *will* change and do as you want me to. Just don't send me away. Please!"

And true to her word she changed. She became disciplined and studied so well that she topped her class. Now she has a respectable job and lives well.

Babu Kaka told us about Mohammed who begged on the streets but who is now employed in his workshop and seems to have forgotten that he is disabled. Babu Kaka once asked him, "I'm sure a day of begging on the streets is more lucrative than working here for the same time. Why do you work here?"

Mohammed said, "Yes, sure, but even the sweets I bought with the begging money didn't taste great. The simple chutney-bhakri which I buy now with my hard work and honest income tastes much sweeter."

How fortunate I was to have been able to spend some time with three outstanding people who had spent the larger part of their lives working for disabled people!

Within a short time, the Secretary of the Paraplegic Foundation phoned me saying, "We've made arrangements for your travel expenses. Tomorrow I'll come for your signature to get your passport ready." What about the other two candidates, I asked. I was told that since they belonged to Gujarat, the Foundation in Gujarat would take care of it.



I finished all the passport formalities and returned to Kolhapur to prepare for the trip. By then, the news that I was to go to England had spread all over town. Sharad Samant, the then President of the Leo Club, (today, the auditor of Helpers) was concerned about me. He asked me about the events I was going to participate in and whether I had the necessary

equipment to practice with. I had nothing. He got me a javelin, shotput and discus right away. I began to practice every morning and evening with help from my friends and sisters. Dr Gajanan Jadhav, President of the Lions Club invited me in order to felicitate me before my departure. I arrived in Mumbai, ready for my trip.

Bhaisaab checked my warm clothes and finding just one sweater, got me an additional warm housecoat, a pullover and a muffler from the market. I had packed mostly saris. A physiotherapist, Reena, was to be my helper and accompany me to England. But she hadn't shown up at Rehana's house even once. I wanted to brief her about what things I'd packed, what I needed and so on. At last, I managed to get her phone number.

She was most casual, "I don't need to come over and see you. I know all about paraplegics, I see them everyday. I'll meet you directly at the airport." I had no information about the other participants either. They were not there at the airport. Perhaps their funding couldn't be arranged for, I thought.

At the airport, when Reena saw me in a sari, she exclaimed, "Eh, what's this? We're going to *England*, not Pune. Shouldn't you be wearing western clothes?"

"Reena, I really like the sari. And I'm going to England to play, not to parade my clothes," I said firmly, already irritated by the lady's attitude.

Rehana was signalling frantically, indicating that I should simmer down. Bhaisaab handed over all my money to the lady since I had to be carried into the aircraft. As I was waving goodbye to my family, I couldn't help wondering how helpful this "fashionable" lady would be. Rehana and Aziz hugged me and Bhaisaab kissed me on the forehead just like Vijay Bhai. And again I was reminded of Baba.

I told Reena to ask for a window seat for me.

"Don't be childish," she snapped back and I kept quiet. There was some fuss about seatbelts and announcements and then we took off. I was really upset that I couldn't see the view outside and I cursed Reena under my breath. I should have asked the cabin assistant personally for a window seat, but I didn't have the confidence. By then I lost both my enthusiasm and appetite thanks to my churlish helper. The



urine bag near my foot was full and I needed to have it emptied. "After we reach England," she snapped again. That meant another fifteen hours!

I now began to sense what was in store for me. I had already lost my appetite. Now I stopped drinking water, sherbet or tea because my urine bag was full. Thanks to her, I may not even be alive to return to India.

England at last! The aircraft door opened on to a platform. I was gently put into a wheelchair and taken down an escalator to a taxi. The organisers were there to receive us. At London airport, I emptied my urine bag and washed my face with very cold water. And then I had a long drink of water. Now I was ready for our taxi ride. We were headed for Elsbury near London.

I noticed how clean and grand London was! I'd been thinking all the while that I was about to set foot on the land of those who ruled India for such a long time. Though I felt a little queasy recalling our complex history, the uneasiness vanished as I began to interact with the English people and was treated with the utmost politeness and affection. I loosened up and decided to make most of the opportunity that I was lucky enough to have got. I tried to take in as much as I could. It was beautiful outside; I saw mostly cars on the road, no auto rickshaws like in India. We passed beautiful green pastures and I saw some cars parked by the road and people enjoying a picnic. It was the month of August. By the time we reached Elsbury it was dark. I asked Reena for help to go to the toilet. As usual she was rude, "All my patients are self-reliant. You should learn to manage on your own." She ordered me to come to the dining hall when I was ready and then left me alone to fend for myself.

I fought back my tears and decided that it was best not to eat. My body was aching after the long flight and it was freezing cold. I was exhausted and went to my room to sleep. But the bed was at a much higher level and I couldn't have climbed up on my own. There were girls from Japan and other countries. They had their helpers with them, so with their help I lay down. Tired and without food, I covered my head and fell into a deep sleep.

It was snowing when I woke up. I brushed my teeth,

washed up and went to the dining hall to see what was on offer. Everything was cold. The tea was hot but the milk cold, so when I added the milk, the tea became a cold drink. Finally I had some ice cream in spite of the cold weather.

I got introduced to the other competitors. There were teams from forty-eight countries speaking as many languages. Since everyone spoke broken English I didn't feel too out of place. Still I didn't speak much, and when I wanted to be understood, I used gestures. My sari was a hit, with many people wanting to be photographed with me. I didn't have a camera then as I do now.

Everybody was getting ready for the wheelchair race. Among all those shining, lightweight wheelchairs on the track, there was my old, heavy one which I'd been using for the last six years. The rubber tyre of the small front wheel had the habit of slipping out occasionally. I was in two minds whether I should participate. Just then the race started and as luck would have it, the tyre *did* slip out. The other wheelchairs raced ahead but mine stopped right in the middle. I was heartbroken because I would never know where I stood in comparison to the other nations.

The Secretary of the British organising body saw me stop and came over to where I sat helplessly. She placed a gentle kiss on my cheek. Something warmed up within me and I immediately took a liking to this kind, gray-haired lady. She saw the broken wheel but didn't mention it. She merely asked me where I wanted to go. She pushed my wheelchair using the two rear wheels to the basketball court where I wanted to go to nurse my grief in silence. She left me sitting there.

But the basketball court was hardly a place to be silent or sorrowful. I was stunned by what I saw. I forgot all about the wheelchair race as I watched young players playing basketball on wheelchairs with such amazing skill. My eyes darted from D to D, all over the court, wherever they went, everywhere. When they were near the basket they would let go of the wheel and zoom in at great speed to basket the ball! There would be great cheering and clapping. Sometimes the wheelchairs crashed into each other. When they fell, helpers would rush in and seat them back, but never once did the ball leave their hands! The javelin, discus, and shotput—events



I'd trained for, were going on, but I couldn't participate because of my wheelchair. But for the time being, I was so taken up with the basketball game that it didn't matter. The energy and happiness on the smiling faces of the players was mesmerising. I knew then that I wanted to wipe away forever, the black mark of misery that was stamped on the disabled people of India and replace it with the same bright confidence that I saw on this court.

I was still watching the game when the elderly lady, whose name I now forget, came to me with a beautiful wheelchair. She said, "This is our gift to you." She helped me into it. She didn't use the words, "donation" or "free distribution," instead she used the sweet word, "gift."

"Are you happy now?" she asked kindly. "Every year we give away three or four wheelchairs as gifts." She gave me the sweetest smile, touched my cheek and started to leave. I took her hands in mine with gratitude and could only say, "Thank you."

The game ended. My new wheelchair flew like the wind on the smooth court and I wheeled around deliriously. The players packed up their stuff and were going to get a bite to eat. They urged me to join them. But everything was just boiled and my stomach churned at the idea. So I made do with just a few spoons of ice cream, though it was funny to have ice cream in that cold weather. I rested for a while and went for a table tennis game.

I spun around in my brand new wheelchair and won the first round. I was ecstatic! I was to play the next day again. The competition was to last three days, after which I wanted to go sightseeing and also get a gift for little Kausar. I'd spent no money at all since I set foot in England, except on some salted peanuts once and that too only when Reena was with me. In fact, she was the custodian of all my money; I had no idea how much Bhaisaab had given her.

Everyone was getting ready for an evening of cultural exchange. I heard the music and saw tables laden with beer, whisky and other alcoholic drinks. But I didn't feel like being there so I quietly went to my room and slept. The next day, I went for the table tennis match but lost. But I was not sorry, on the contrary, I was happy just to participate.

My sari continued to be a great hit with several requests from many participants to be photographed with me. Reena, who earlier, had viewed my sari with utter disdain was now watching all the fuss over me. One day, while I was in my room she said hesitantly, clearing her throat,

"Uh...hummm...Naseema, can I borrow one of your saris?"

I knew that nobody had bothered to notice her in her "modern" clothes.

"Sure," I said, "help yourself," not asking any questions.

I must say, that despite her most surly temperament, she looked rather charming in one!

The games were over and it was the last night before people returned to their countries. It was party time. I decided that I would sit in a corner and observe how they partied here in England. There was much drinking and dancing, mostly on wheelchairs or crutches. The party was in full swing. A young Englishman came towards me with two glasses in his hands.

"Hello! Are you alone?" he asked. He offered me one of the glasses saying, "Here, have a drink, you'll feel less cold." It was cold and I'd covered my head with my sari pallu.

"I don't drink. You see, Indian women usually don't drink," I told him.

"Nonsense! I go to Mumbai very often. Girls not only drink but are quite free to mix around. What you Indian women do secretly, the women here do openly. That's the only difference," he said.

I wasn't in the mood to argue with him. "Will you leave me alone, please?" I said. "The smell of alcohol makes me a little sick."

No sooner had the white man left than a black youth approached me. He said, "Hmmm....your lovely black hair is hidden under your sari. You look beautiful! Why don't you come dance with me?" I refused politely.

Then he started touching my sari and tried to uncover my hair. I lost patience.

"If you don't leave me alone, I'll have to raise my voice. Why don't you dance with the girls who are more willing?" I must have sounded very firm because he disappeared instantly.

Just then Reena, who was preening around and making



quite a show of herself in a sari, came to where I was sitting, accompanied by a male English physiotherapist.

I told her, "Could you wait a little right here, I'd like to go to my room after this dance is over and I need your company. I don't fancy being waylaid by another drunken lout!"

"I'll be back in a moment," she said. "This gentleman here has offered to show me the physiotherapy centre. Wait here for me."

And then she was gone before I could reply. I thought to myself, "The physiotherapy centre at *this* hour? Besides, she's gone alone with a total stranger. Oh well, she's not a child, she doesn't need *my* advice. I only hope she doesn't have to regret her action."

In a few minutes she came back panting and fuming, saying "Oh my God, I should never have trusted him. You know what? He misbehaved with me!"

I couldn't help saying, "There's a party going on with lot's of drinking, for God's sake. What were you thinking going off with him to a place which is not even *open* at this hour. What did you expect him to think?"

"Why didn't you stop me?" she asked.

"Why would I stop you, you're an adult," I said.

Anyhow, we slipped back to our rooms and slept. Superficial and shallow that she was, I felt relieved that she, at least this once, stood her ground like a dignified woman.

A few days earlier, Reena had asked casually, "By the way, how did you get your new wheelchair?" I told her about the gift. Now, as I was packing and putting away my things, she sat on the edge of my bed.

She said, "Look, I have a wheelchair that's even better than the one you've got. Can you take this with you to India? It's for a patient of mine. Don't worry, I'll ship your old, broken one to India at my cost."

I couldn't get her drift. What was she trying to say? Bewildered, I asked her, "If you want *me* to take this, does it mean that *you're* not coming with me?"

She acted surprised, "Weren't you informed by the Foundation authorities in Mumbai? Whenever we come here, we take the opportunity to attend a three months physiotherapy course. My relatives are coming to fetch me.

I'll be going with them and will return to India after the course. There'll be someone to take you to the airport."

I couldn't believe it! I was so dumbfounded that it took me some time to grasp what she was getting at. She was my *helper* with instructions to stay by my side, but I had to make the journey back to India all by myself! For almost six days now I hadn't eaten or taken a bath. And I'd had no help at all for my other personal needs.

Angrily I told her, "Well then, call Bhaisaab in Mumbai and tell him that I'll be coming alone and that he should have me picked up from the airport."

"But it costs so much to make a call," she said.

"Well, you have my money, use it. I'll come with you."

"Oh, no," she said, "I'll go alone, the telephone is really far away."

She disappeared for a while and then came back, "I've told them. They'll be there to receive you. Don't worry."

By this time, I'd lost all trust in her. I said, "If I find no one at the airport, I will call Vijay Bhai and hold a press conference to expose all of you. You come here at the cost of us paraplegics and do what you please. Besides, I'd like to know what kind of 'course' you'll be taking."

She pretended that she hadn't heard me and began saying her goodbyes. That was the last straw. I was furious!

"You can't say goodbye to me *here*! You will have to come with me to the airport and seat me in the aircraft," I insisted. I never had such an uneasy feeling before. She hadn't given me back my money though I asked for it twice. Instead she gave me a wheelchair and a bag which I was to hand over to her brother who *I* was supposed to call on reaching Mumbai.

Finally, as I was wheeled into the aircraft minus Reena, I requested to be seated by the window. The man smiled and gave me a window seat. Soon we were airborne and I forgot all my worries. I was on my way back home. After all these days, I ate Indian food on the aircraft, including hot, sweet carrot halwa. That was the end of my six-day fast.

We had a stopover at Paris. As we were landing I saw the flickering lights of the city and imagined how well laid out it must be. The panorama below us was right out of a breathtaking dream. As we flew through clouds and over



valleys and mountains I dozed off soon to be woken up for tea which was being served. Just as we were about to land in Mumbai, my anxieties reared up again. What was I to do if Bhaisaab was not there? I had no money with me, not a single paisa. I didn't even know how to make a phone call from a public telephone. Even if someone did help me, I didn't have a coin. I just prayed and prayed.

I was wheeled into immigration and then through customs and finally into the reception area. And there, through my dense fog of fear, I saw Bhaisaab waving to me from behind the glass partition. God did hear my prayers! I was almost near the exit. An airport trolley carried my suitcase along with Reena's bag. On top of the luggage was the new wheelchair, folded.

Back home, I headed straight for the bathroom. After a nice bath and hot, home-made food, I slept like a child. When I woke up I noticed that Aziz and Bhaisaab were curious about the other bag.

"Whose bag is this? Did you pick up someone else's bag by mistake?" they asked.

"No, I didn't" I said.

"Well then, let's see what's in it. It could be something dangerous."

The bag contained a nice player's jacket, several soaps that were kept in the bathrooms, perfumes and other things. I recognised some of the things as belonging to the other participants. Nothing looked new, so it was clear that they were not bought from the market. This woman was nothing but a petty thief!

My family, who didn't know what happened, was shocked. Could it be that their own, dear Naseem picked up these things in a weak moment? Could she actually steal? Their expressions were worried. It was then that I told them the whole story about Reena and her duplicitous behaviour.

"The bag and the new wheelchair belong to her. Her brother will pick it up from us," I said.

Bhaisaab scolded me, "Naseem, what you've done is crazy! Let's assume that the airport authorities had found, say, hashish or opium in the bag, what would you have done then?

Gone behind bars, that's what! You should've insisted on seeing what was in the bag."

They were right, of course, but only I knew how confused I was then.

Aziz was furious. He said, "Reena has put you through so much anguish. I have half a mind to not give her brother the wheelchair and the bag. We'll give them to someone who really needs it."

I had already informed the brother that the articles were to be picked up, so I said, "No, we should give it to them and then, let *them* work out their own karma."

Meanwhile, Fatima Ismail asked me to write an article about my trip to England. I sent them an article titled, *Misfortune in the Midst of Fortune*. It was published in the journal of The Fellowship of the Physically Handicapped.

I was now ready to return to Kolhapur to devote myself full time to the work I wanted to do. The new wheelchair served to strengthen my resolve.

But before that, I must tell you, the Reena story didn't end there. I got a letter from her which said, "I had to leave your old wheelchair in England because it was too heavy and expensive to have it shipped to India. Besides, I had to pay the English organisation for your new wheelchair. You should either send me the money or return the wheelchair to me." She had even mentioned the amount.

"Pay? I thought it was a gift!" I was shocked. "No, no, it can't be...the kind grey-haired English lady..."

As I mulled over it, feeling betrayed, the picture began to emerge. I began to realise how things worked. These physiotherapists from the Paraplegic Foundation have made a fine art of cashing in on the misery and gullibility of the disabled. Their extortion techniques were the same year after year. They cheat and extort wheelchairs out of those who receive them as gifts and sell them to the rich at good prices—an excellent way for the unregistered institute to make money.

This was a racket, plain and clear, and I wasn't going to take it lying down. I wrote to Reena, "Send me the receipt for the wheelchair that you paid for and I'll pay you back." I also rushed off a letter to Vijay Bhai.



The Director of the Paraplegic Foundation that supplied these helpers to paraplegics like me, wrote me a hypocritical letter saying, "We are getting the Foundation registered. You must become its Secretary." Naturally, I refused.

Soon after, Vijay Bhai founded and registered an organisation called The All India Paraplegic Sports, an apex body, mainly to ensure fair selection of teams for various competitions. I was part of the management. Teams had to now go through this body.

Aziz and I were on our way back to Kolhapur. At Pune station Aziz yelled, pointing at someone, "Look, look! Isn't that our old friend?" And so indeed it was! It was Ashok the rake! And guess what, this time he was *standing* on his two legs! He was walking along happily though he had a stick for show.

He was passing by the window of my carriage. I hailed him, "Hello Ashok, for a paraplegic you seem to be doing very well!"

"It's my will power that makes me walk," he replied, limping a little extra.

"Oh then, can you please be my guru and help me strengthen my will power so that I too can walk?"

"Not everyone can do it," he said haughtily and walked away hurriedly. I remembered the gold medal which he said he'd won abroad. I chuckled to myself. The man had carved a fine living for himself by proclaiming various types of disabilities depending on the occasion!

I was bursting with ideas after I returned from England. I wanted to set up an institution that would promote the rehabilitation of disabled people. I wrote a story called *Kaho Na Aas Niras Bhayee* (Don't Say that Hopes will Turn to Disappointments), a narration combining my dreams with some real practical information. Now it so happened that the weekly *Swarajya* announced a story-writing competition just then. Since my story was ready I sent it in. It got published. I had always had a special relationship with this weekly magazine, a bond that was established long ago by a poem that I read in it. The poem went deep into me and inspires me to this very day. It is our morning and evening prayer at Helpers. It goes like this:

*Grant me, oh Lord, both joy and grief  
But also the strength to bear it all;  
Strike me with failure if that's what is destined  
But give me the key to bring a smile to all.  
May we be able to create a rainbow  
In each teardrop that rolls down the eye  
And also to weave the fabric of life  
With the vibrant threads of grief and joy;  
Bless me, oh Lord, with the ultimate faith  
Firm like Dhruva, the Northern Star  
Then let the fires of affliction burn  
'Cause hope will bloom through all the strife.*

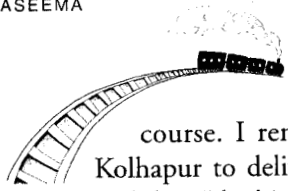
Around that time I read the biography of Helen Keller and another book, *Give us the Tools* by Henry Viscardi (The same book is now available in Marathi as *Haat na Pasaru Kadhi*). Helen Keller who was blind, mute and deaf, showed the whole world what determination could do, and how it is possible to work for others who are similarly afflicted.

Henry Viscardi, who'd lost both his legs, started a factory run by disabled people in America. A lot of the factory hands had to work in a lying-down position. The book spoke about the disability of each person, assessed his capabilities and weaknesses, and how they found a way out of their problems. Babu Kaka was my guru, but now I had two more. Even today, when I'm depressed, I go back to these two books again and again.

Later, I had the good fortune of meeting Henry Viscardi and his wife at a conference. I couldn't contain the excitement of meeting the man himself, my guru and the protagonist of the book that so touched me! And for the first time I felt truly handicapped at not knowing enough English to have a hearty chat with him. If only I'd studied in an English medium school. The other thing I regretted was not having a camera so that I could be photographed with this great man. My pride stopped me then from asking someone else for it. Now, many years later, I have a camera that Aziz gave me. Nothing stops me from taking as many pictures of our children as I want.







Not having any sensation in one's legs has its own advantages as I came to learn in due course. I remember an incident when Rehana came to Kolhapur to deliver her baby. Ma had to stay in the hospital with her. I had just one day before I went to Mumbai to attend a meeting for a sports event, so I decided to relieve Ma from her hospital duty for that day by attending on Rehana. We had taken a special room in the hospital which included an attached kitchen. Just as Ma left for the day, I realised that we didn't have enough boiled drinking water. I went to the kitchen to boil some water for us though Rehana objected. The kitchen counter was a bit too high, still I managed to light the stove and put a pot of water on it. When the water boiled, I looked around for a grip to remove the boiling pot from the fire. But since there wasn't one, I used a piece of cloth. I don't know how it happened—maybe because I had no sitting balance or the kitchen counter was too high or the cloth slipped—the boiling water fell all over me.

It so happened that the doctor was doing his rounds just then. He spoke to Rehana in the other room and because I didn't want to be seen, I kept to the kitchen till he left, all covered in boiling water. Since I was all wet, I wanted to peel off my clothes in a hurry. So I went to the other room and started taking my clothes off. (Normally I change lying down on the bed). When Rehana saw my skin, she gasped in horror. It was all burnt, blotched and peeling. She started crying. I consoled her by saying, "Thank God my face isn't burnt!" Apart from the upper part of my stomach, which was burning, I couldn't feel anything lower down. As I said earlier, the lack of feeling turned out to be blessing in this case.

Be that as it may, what was I to do next? Dr Gajanan Jadhav, my doctor, always let me do as I pleased. So I just emptied a tin of talcum powder on the burns. But that was a huge mistake as I discovered. Anyhow, I took an injection to prevent infection, got my wounds dressed and leaving everyone else to worry about me, left for Mumbai as scheduled. This meeting was to be a landmark one, because I was opening an important door for a sports meet for the disabled citizens of Kolhapur, for the first time.



Aziz came to see me off at the train station. His friend, John was to accompany me to Mumbai. Rehana was in Kolhapur to have her baby and so I decided to stay with my aunt and uncle who would escort me to the meeting. I was to disembark at Ambarnath, a suburb of Mumbai. We saw the ticket conductor boarding the train. Aziz patted me on the arm saying, "Take care of yourself, particularly your wounds. Do write to us." No sooner had he said that than I had a thought—is it fair that I should be going to Mumbai keeping everyone worried about me? For one thing, I knew Ma wouldn't eat or sleep till I got back. But I also knew that this was a not a meeting that I should avoid.

The train moved and the conductor came to check our tickets. When he saw our tickets, he said, "This particular coach won't halt at Ambarnath. You will have to change over to another coach in Miraj."

I was horrified. "But the train stops at Miraj for just thirty minutes!" I thought to myself. "How was John, all by himself, supposed to transport me to the other coach with my wheelchair and baggage?" I felt the mounting tension as only a helpless disabled person would feel. I wouldn't be at peace till I actually moved to the other coach and sat down. Actually, I should say, lie down, because I have to always travel lying down. I was younger and stronger those days, so I could travel in an ordinary second class coach.

At Miraj, John hastily pulled out the luggage first, then the wheelchair. He carried me and put me on it. Then we dashed off to the other coach. When he saw us, the conductor of that coach was astonished, "I'm sorry, you can't sit here. Why did you leave the other coach in the first place?" Saying that, he forced us to get off.

We dashed off again to the earlier coach. John just about managed to shove me into it and the train moved. Luckily I didn't fall down. I felt so bad that John had to go through all this because of my stubbornness in wanting to go to Mumbai for the meeting in the first place.

Fortunately, John was spared another ordeal of lifting me again and depositing me elsewhere, because the gentleman who occupied the lower berth got up saying he would take the upper berth. As usual, the conductor began to ask whether



we had paid special “luggage” charges for the wheelchair. I whipped out a circular issued by the Railway Department which said that wheelchairs are exempt from any charges, and a copy of the letter that Babu Kaka had written to them once about how conductors routinely take advantage of the ignorance of disabled people and harass them. The conductor didn’t expect that we would have so much ammunition under our belt and went off sheepishly.

So there we were, still none the wiser for knowing whether this coach would go to Ambarnath. I’d lost my appetite, but Ma had packed some food for us and I felt that I should eat something so that John would eat as well. But he couldn’t eat much either. In spite of the cold we kept the shutters open so that we wouldn’t miss our station. I put on a warm jacket and covered my head with my sari. Close to Ambarnath, John moved the luggage near the door so that we wouldn’t lose any time. But, oh my God, we trundled past Ambarnath, *dhad dhad dhad*, and in two minutes, the station was left far behind. By now I was totally shaken and my heart was beating louder than the sound of the train. We had tickets only up to Ambarnath. Rehana was not in Mumbai either. What was I to do? I suddenly remembered that I had a younger cousin, Aasifa, who always said, “Call me if you ever need any help.” She was in Mumbai with her elder sister. I decided to call her.

We disembarked at Dadar. We had to pay a fine for getting off at the wrong destination, and when we finally left the station, we tried to call Bhaisaab, but couldn’t get through. So we decided to just go to Khar, to Rehana’s house. It was a miracle that I was able to remember Rehana’s house. I was so bad with directions, that I still can’t locate my friend Rajani’s house in Shukrawar Peth, right in the heart of Kolhapur! Sensing some trouble, the taxiwala, shrewd businessman that he was, demanded a hefty amount as he dropped us off. I asked John to get Bhaisaab and lo and behold, just as soon as he saw Bhaisaab, the fare came down miraculously! Bhaisaab paid him and carried me all the way up four flights of stairs. He couldn’t quite believe that we had reached his place instead of my uncle’s at Ambarnath.

As he deposited me on the sofa Bhaisaab joked, “Serves you right, Naseem for not coming here in the first place just because your sister isn’t here. Now see what happened. You’ll

see that your brother-in-law is not an ogre after all!” Unfortunately, I was so traumatised by the entire experience that I was in no mood to laugh.

I said, “Please put me on a bed, I’m very tired, I need to lie down. John will tell you what happened.”

I felt feverish and my body ached all over. Bhaisaab could see that all was not well with me. He told his cousin, Badshah Bhaijaan’s wife to give me whatever help I needed. Then he had to leave. I badly needed a wash, so I told Bhabi to get me some water in a basin and please wait outside. I was dying to change out of my sari which seemed to stick to the burn blisters and which had now begun to ooze. When I boarded the train at Kolhapur I thought that it would be a quiet affair where I would just lie down during the journey. I removed my sari and put on a gown. When I saw the wounds I choked in despair and began to feel dizzy. The skin had peeled off from some of the blisters and there was a crop of new ones. My hands were trembling as I pulled out the tube of ointment from my handbag and applied it. I said to myself, “Dear God, why are you testing me like this? How many more tests have you lined up for me? I’ve have had enough!”

Bhabi was at the door asking, “Can I come in now?”

I wiped my tears and washed my face. Somehow I managed to eat a little. Bhaisaab was back and now I requested him to call cousin Aasifa. Since I couldn’t move without help, it was difficult for me to nurse the wounds on my bottom where the boiling water had seeped in under my clothes. Aasifa was younger than me and though it was awkward for me to ask for such intimate help, I had little choice.

Meanwhile, my uncle in Ambarnath, worried at not seeing me, telephoned Bhaisaab to find out about me and was relieved to know that I was safe. I was anxiously waiting for Aasifa who came at about four. Bhaisaab placed the phone near me when he went to work. Badshah Bhaijaan got me a tape recorder so that I could listen to music. Bhabhi made hot food and insisted we eat. All this affection and care have been my good fortune again and again, giving me the strength to fight the unhappy situation that was now my lot.

I took Aasifa aside and said, “I want something from you. You must say yes.”

"What is it? Well, okay, yes!"

"Close the door. Now come here and take a look," I showed her the nasty blisters on my bottom. "Promise me you won't tell a soul about them till I finish my meeting tomorrow for which I've come this far. If you tell anyone, that's the end of my meeting." When she saw the blisters she wondered whether she should actually keep quiet, but then, since she promised, she agreed.

"But first," she insisted, "let me take care of your wounds." She sponged me down and applied the ointment.

"Can you prick the new blisters?" I asked her.

"Oh God, no, I don't think I can!" she said squeamishly.

"Well, if we don't, the ointment is not much good," I said. Saying this I began bursting them one by one with a little help from Aasifa. She wiped the blisters dry and spread the ointment on them. I fixed my hair, put a little powder on my face and felt much better. I sat leaning on a pillow, much calmer than when I came in. Soon Bhaisaab, Bhabhi and Aasifa were chatting.

Bhaisaab said sarcastically, "Naseema seemed so glad to see Aasifa, as if we couldn't have helped her!"

Bhabhi complained affectionately, "You're right. I've been asking her since morning what she wanted but she seems to have put a lock on her mouth!"

Bhaisaab noticed that my eyes were getting moist and changed the subject. He placed a sari in my hands and asked, "Do you like this? I'm celebrating because I've become a father!" It was a beautiful sari. The next day he was going to Kolhapur to see the baby.

I went for the meeting at the appointed hour and spoke on behalf of the disabled people of Kolhapur. They could now participate in the various sports meets organised by different bodies. I was elected a member of the Executive Committee of The All India Federation of Sports and Rehabilitation for Paraplegics. Vijay Bhai was elected President and Mr Masalawala and Babu Kaka were Secretaries. Vijay Bhai greeted me with great affection as always.

By the time I reached home I was exhausted. I switched on the radio. There was a song playing—"gam ki andheri raat men, dil ko na bekarar kar, subaha zarur aygi subaha ka intazar

kar." It meant, "don't despair in the dark night of sorrows, wait for the dawn, the sun will surely rise."

With the meeting over, I now decided to call Bhaisaab and tell him about the burns and the need to consult a doctor. As expected, he scolded me for keeping it a secret, but still he came home with a doctor. I was given injections and medication.

The sports meet, which was being planned in Mumbai, was to take place soon. I was advised to continue staying in Mumbai and not bother to strain myself returning to Kolhapur and then coming back again. Yes, certainly, that was more sensible. John, however had to go back. I wrote to three disabled people in Kolhapur who I felt should participate in the games.

Fortunately, they did well, winning medals and honour for Kolhapur. I returned home with them. It took two months for the wounds to dry but I didn't spend more than eight days in bed. Work is the most effective medicine.

Through Babu Kaka I came to know many other disabled people. We decided to open a rehabilitation centre in Kolhapur. Some of the prominent townspeople came together to work out a constitution for what was to be called Apang Punarvasan Sanstha.

We gathered at my home to read out the new constitution. Ma was more than happy to make tea and snacks. When the time came for the selection of committee members, I was dropped because of my inexperience. Rajani Karkare, Ranade, Patankar, and Bhosale were the "disabled" members. Mr Gokhale, who attended our meetings for the first time, formed the Committee. The papers were handed over to him as he was the Secretary. The Sanstha (institute) was now ready for registration. I was to be in charge of the vocational training center which was a little space in the hall used by the Rotary Club near the blood bank. That was how I spent the years 1974 and '75.

I wrote up a report on the meeting and sent it to Babu Kaka. I told him that I needed information on a variety of



things to start the training centre. For this I would need to go to the government small industries department. I realised that I would have to contribute some personal money to this venture so I started giving tuitions at home and also did some stitching and crochet work. At the same time, I started looking for a job.

I had already written to Babu Kaka about my England trip. I told him that I still needed to be accompanied when I went out because of the danger of the catheter slipping out. Earlier, with the old, heavy wheelchair I had no option but to take a taxi, but now the new one could fit into a rickshaw. So, now sometimes, I could go out alone. Also, when I heaved myself into the rickshaw on my own, I had less leg-spasms than before. The bedsores were quite troublesome though.

Soon after, I got to know that Babu Kaka had leukemia.

Babu Kaka replied almost immediately. This was rather unusual because he usually waited till he got at least three or four letters from me and then would write at one go. And even to do that he would finish off the day's work and write late at night. He used to write the time on the letter, usually well past midnight. So I almost felt guilty writing to him, resolving that I would disturb the ailing man as little as possible. But this time I couldn't hold myself back.

Babu Kaka wanted me to call him as soon as I received his letter which I did from the nearby Woodland Hotel. Just hearing his voice was enough to make me happy. He asked without much preamble, "Naseem, why isn't your name included in the Committee? Is it a mistake?"

I told him, "It doesn't matter if my name's not in it. What matters is that *I'm* going to run the training centre. In fact, Rajani was very keen that they take me instead of her. She told them that she wouldn't be able to work as hard as me and that all this has come about because of me. But the decision was unanimous that I was too young and inexperienced. But, Babu Kaka, how does it matter whether I am in the Committee or not? You wait and see, the next time you come to Kolhapur, you will be visiting a fully functioning vocational rehabilitation centre!"

He said not letting go, "Is it because you are not a Brahmin?"

I was shocked, "No, no! If that was so, why would they give me the responsibility of the training centre?"

"Well Naseem, you know best. Anyhow, I'm on my way to Pune for my chemotherapy. Can you and Rajani meet me at Miraj railway station? You could come in Bal Janwadkar's car."

I couldn't possibly refuse.

Babu Kaka looked wan and thin when we met him at Miraj. He told Janwadkar and Rajani that I *must* be included in the Committee the following year. It was almost an order. That day I decided that I must fulfill two of Babu Kaka's most cherished wishes while he was still alive—run a training centre and organise sports competitions for the disabled living in Kolhapur.

I launched into work, full swing, with Uncle Vasant's help. Slowly, the training centre began to take shape. At the Small Industries Department I learnt to make chalks, cardboard boxes and plaster models. Initially I started with five disabled people. I delegated jobs—filling moulds with plaster of paris, applying oil to these moulds, drying and making cardboard boxes for packaging—each according to their own ability. But when I was not physically present, they tended to slack off and production became sluggish. Once I caught them off guard. They were whiling away time, smoking bidis and chewing tobacco. I realised how difficult it was to bring about fundamental attitude shifts in fully-grown adults, almost as difficult as imagining that surgery would be the real answer to alleviating disability. And equally difficult was the job of inculcating the work habit. But Bandopant More and Laxmibai Jadhav were the exceptions.

The training center officially began on 8 February 1975. Though I hadn't asked for anything, the management thought it fit to give me an honorarium of one hundred and fifty rupees. I put aside fifty rupees for the person who helped take me to the centre and bring me back. One day, I had an idea—why not entrust this job to a blind person? I wanted to experiment with this idea and even tried it twice, successfully. The blind man would navigate me while I acted as his eyes, warning him about stones or ditches on our path. But Ma, fearing for my safety, was dead against this experiment. After a few days, I decided to do it alone. I started

negotiating the downhill slope near the Kiran bungalow all the way to the Shahu Blood Bank where we had our centre. Coming back up the slope was difficult, so a woman was engaged to bring me back home.

One day, a forty something woman named Jadhavbai came asking for a job. She was paralysed on one side. She had a son, Raju. She was our first woman trainee at the centre and was a good worker. At night she lit a stove under a tree and did her cooking. A few days later, Sukumar, a young mentally retarded orphan girl started living with Jadhavbai. I noticed that they had stopped cooking during the rains. So I asked Ma, "We have a big house. Can we let the three of them stay here till the rains are over? Sukumar could help you with the laundry and dishes. Raju goes to school and Jadhav Mavashi will be busy at the centre. It's only a question of allowing them to sleep here at night."

Ma said, "That may not be possible. But I can give them lunch and dinner."

She also gave them old bed sheets and clothes. And for three months she fed all three of them.

Babu Kaka came to Kolhapur during Diwali vacations. I was eager to show him our training centre, but he was so ill that he could come only once. I told him that our trainees were happy about the small stipend they earned every month, but how long could we keep making just chalks and idols? I was toying with the idea of making office files and supplying them to various offices. I'd already done some groundwork on this and knew where to get the raw material and machinery from. A sports competition for the disabled was also in the offing. A brochure for the occasion was being planned and we would collect revenue through advertisements. We would then funnel this revenue into our office-files project. I went on and on, bursting with enthusiasm which his encouraging expression only served to redouble.

For a whole month, till such time that Babu Kaka was in Kolhapur, I took packed lunch to his house and we had lunch together. He had fever everyday. After lunch I would go to the training centre and then visit him again in the evenings. That became my routine. Around eight o'clock, he would say, "Naseem, it's time for you to go home, your mother must

be waiting for you." I was reluctant, but he would insist and send his own helper to accompany me all the way home.

The chemotherapy made him very uncomfortable and he felt a burning sensation all over his body. But there was no fan in his room so I arranged for a table fan. He was advised to eat a non-vegetarian soup everyday but his family were strict vegetarians. I was happy therefore when Ma volunteered to do something about this.

She said, "Ask Babu Kaka to send his helper to collect the soup from our place at the time when I've just made it. There's no point sending it with you in the morning, it'll only get cold, and they may feel squeamish about heating it up." He needed to have this nourishing soup twice a day.

I pleaded with Ma, "Please let's bring Babu Kaka here for a few days."

Ma was not very keen on this, saying, "What about society? What will they say? We can't possibly do that."

"Society? What society?" I was angry. "Did society come to my help when I was bedridden? When I was down and out? So what right does it have to make rules for us?" But I had no answers, only angry questions. I didn't know how long I would have Babu Kaka's company and each day saw me returning home late. But Ma understood even if I returned as late as nine. She said nothing.

I felt lonely when Babu Kaka went back to Bangalore. The training center was in progress and took up all my time. I began to get my project papers ready. Soon I presented my proposal regarding the sports meet, the souvenir and the file-manufacturing unit to the Apang Punarvasan Sanstha. I wanted all this to happen by 8 February 1976, the first anniversary of the training centre. I had watched Babu Kaka organise the sports meet in Bangalore very carefully, so I felt equipped to arrange one myself. But I didn't know that there was a surprise in store for me.

The Committee scrutinised my proposal and made its declaration, "Why do we need such a sports meet? Who will come? What will they play? And where will the money come from?" It was very clear that their response was negative. I was not even given an opportunity to speak at the Committee meeting. After all, I was only a supervisor who received an

honorarium, just an employee. That day, I realised why Babu Kaka was so upset at my not being on the Board. But Rajani gave me her total support.

I insisted, despite their disapproval, that we call a meeting of all the disabled people we know and put our proposal before them. Perhaps we *could* make a difference. We told them that we were going to set up a new sports committee and after the meet, any money saved would go into buying the machinery for starting the office-file manufacturing unit. Money earned from that would then be donated to the training centre of the Apang Punarvasan Sanstha. The plan was unanimously approved; duties were delegated and soon our project on paper was becoming a reality.

Rajani took over the souvenir, collecting advertisements and articles in no time. Many people offered to donate food and snacks. Surprisingly, we got lots of donations. One day, while I was working at the training centre, General Thorat, Trustee of the Sir Pirajirao Ghatge Physical Education Charitable Trust and Mr Vikramsimha Ghatge dropped in just like that, and gave us a cheque for five thousand rupees. Unbelievable luck! Our enthusiasm doubled. We called an emergency meeting in which we decided to involve athletes from *outside* Kolhapur, especially some of the better-known players—players of international repute. A private high school offered its premises to house the visiting athletes where we made special arrangements keeping in mind the problems associated with disability. The school students served as volunteers and did such a good job that everyone was totally impressed. Babu Kaka's sister-in-law, Indumati Diwan, who worked with the Vanita Mahila Mandal, was responsible for the catering.

The city of Kolhapur was buzzing with the event. Athletes came from all parts of the country—Pune, Mumbai, Gujarat and Karnataka. There were jawans from the army and their superiors, the Majors and Colonels. The District Collector came too. That day, there was a gathering of not just one or two but around two hundred disabled people. Such a large assembly of disabled people looked more like an awareness raising programme rather than a sports meet with selected players. Not everyone would win but it will show the people of Kolhapur what the disabled were *capable* of!

Reports and photographs galore of the Khasbaug Stadium sports meet on 8 and 9 February 1976 were published in every magazine and journal which, I thought, was a fair amount of publicity with not too much effort. I sent Babu Kaka all the news telling him how delighted I was to be able to invite the attention of the disabled people of Kolhapur to what extent disability could be overcome. And thankfully, all this happened while Babu Kaka was still alive. On the last day, while some entertainment events were going on, I lay down in the dark, exhausted. The previous night had been terrible.

I ran over the events in my mind...dinner was just getting over. I wanted to make sure everybody had food, including the drivers of the cars. Some friends, who wanted to help us in kind, had placed three cars along with drivers for three days at our disposal. They were meant for picking up the players from their arrival points, taking them to their place of stay, taking them to the stadium and also for taking them around Kolhapur. A person was specially appointed to look after the vehicles. As we went around inquiring about dinner, we realised that a Matador van and its driver were missing as was the person in charge. With Surendra Mali, who was with me all the time as my helper, I took a rickshaw and searched practically every nook and gully of Kolhapur till midnight. A group of volunteers panned out on their bicycles and scooters. Finally, we located him in one of the side streets, blissfully passed out, fully drunk! But the car was in one piece, thank God. I was still up at two to make arrangements for hot water and other things for the morning.

At some point in my recall of the previous night, I dozed off. I was just waking up when I heard two men from the Committee talking outside my window, "How come the press has covered the efforts of only these *two* women? Only *their* pictures have been published. What about us, haven't we worked just as hard?" The truth is that Rajani and I participated only because everyone insisted we do so. And because we did well, the press published our photographs. These men were being stupid. As a matter of fact, I had always claimed that the sports meet was a success only because of *everyone's* efforts, especially that of all of us disabled people. But I had no energy to take

them on just then. I had a fever and a urine infection because of the catheter and felt very weak.

The next day we took the teams on a sightseeing trip of Kolhapur. After they left we took about four or five days to wind up. We had to return all the mattresses, chairs, utensils and other things which we had rented for the event. But I was quite sick and Colonel Watson, Superintendent of the Army Technical School in Pune, who happened to be in Kolhapur at that time, was appalled at my condition. He said, "This can't go on. It's not such a good idea to use a catheter all the time. The infection could be fatal and you have much work to do. I'll get you admitted to the Army Hospital as a special case, you being a social worker."

My urine was as red as blood, so I needed kidney X-rays. I took up Col Watson's offer without the least hesitation; it would save a lot of expenses for the family. I was in Pune by the end of February.

I was so ill that I just couldn't find an opportunity to explain certain things to the Sports Committee who I felt, was hot under its collar because of what we had pulled off. They refused to pay the catering contractor the full amount for his arrangements because he said that the bill had exceeded the budget. That was so because we had given entry, at the last minute, to some athletes from the nearby villages. I was unable to attend the Committee meeting because of my fever, but got to know that at one point, it got violent and abusive. The next day, I took a cheque for the sanctioned amount from our Treasurer, and borrowed the rest of the money from Ma and Uncle. But the contractor was most reluctant to accept money from me.

"I don't think you should be the one to pay. I know how to recover my money from those scoundrels!" he exclaimed.

"Look," I said, "I'm the President of the sports meet and this is my contribution to the future of the disabled people of Kolhapur." I made him take the money. As soon as Rajani got to know of this, she insisted on contributing half the amount.

Bhagwan Patil from Navali, Panhala was one of the athletes. He had two stumps for hands and likewise for his feet. He was illiterate, but swam like a fish and rode an ordinary bicycle. He was on his way abroad to take part in a Para Olympics event.

"What do you do for a living?" I asked him.

"I sell liquor to the villagers," he replied.

"Why do you run a business that destroys peoples' families?"

"What else can I do?" he said. "How do I feed myself?"

But happily for me, when he came back from abroad, he got a job as a peon in the Zilla Parishad office and found himself a nice girl. Now he leads a comfortable married life.

Aziz and I reached Pune. To our happy surprise, some of the athletes from the paraplegic home were there to receive us at the station. I was rushed to the hospital because of my mounting fever. I knew no one there so someone who worked at the hospital agreed to be my guardian. So Aziz gave him some money to take care of my food and then he had to leave. This was the first time that I was all alone away from home. Col Dr Singh, who was a specialist in paraplegia visited me in the afternoon on his rounds with his younger colleagues.

"How come this lady's urine hasn't been sent for examination as yet?" he was furious. "Does a patient come all this way just to lie on a bed?"

Suddenly there was a flurry of activity and my tests were done in a jiffy. He was very particular about cleanliness and discipline and chatted warmly with his patients. I loved his sense of discipline and got to really like this doctor.

I had many visitors, most of them organisers and athletes who took part in the sports event. They were happy with what we had been able to accomplish in Kolhapur. Soon the fever abated and I started moving about, practicing my wheelchair manoeuvres, covering long corridor distances. After that it was table tennis and reading books borrowed from the library. Someone gave me a transistor. But most importantly, I began to discover the world of other paraplegic women, a troubled and different world indeed, and one that was to have a deep influence on me.

There was one paraplegic woman whose husband visited her clandestinely at the hospital. Clandestine because he was sleeping with her. When she got pregnant, the husband panicked because according to army rules he was liable for punishment for impregnating someone who was technically a hospital inmate albeit his wife. He denied having done anything

and then forced her to abort. The paraplegic woman became insane with grief, saying that she had slept with no man except her own husband and wanted the baby. Would you believe it, in two years she had three abortions! She was so psychologically disturbed that she had to undergo shock treatment. I felt so sorry for her that I couldn't even bear to look at her.

And then there was another middle-aged paraplegic woman whom everybody called "Amma," mother. Her behaviour was almost insane. She constantly accused her husband of marrying a very young girl because of her own paraplegic condition. For some reason she had got it into her head that *I* was that young girl! I was supposed to have snatched her husband away from her and for that she would heap curses on me. Her bed was next to mine. Whenever I got ready to go out she ranted,

"Look, see how she's all dressed up to seduce my husband! May she never have good fortune, may she never be happy!"

"Amma, why don't you come with me and see who I'm meeting," I would suggest, but she wouldn't leave her bed. One day, to relieve me of her "harassment" they moved her bed to a corner furthest from me.

"No, no," I said, let her be, I'll be able to convince her that I am not this other 'younger' woman."

But move her they did and even from that distance, her curses rained on me.

Amma's legs gave her excruciating pain, and so the hospital ayah massaged them with oil. One day, I found her crying for a long time, saying her legs ached. Not a single person was around, where on earth *were* they? So I wheeled myself to her bed. I was wearing my favourite white dress but Amma didn't have her glasses on and as I reached her bedside, she held out the bottle of oil. I started messaging her legs with the oil and soon the wailing stopped. Sensing something different, she put on her glasses and took a good long look at me. Then she took my hand in hers and wept uncontrollably without uttering a word.

The crying stopped and the words tumbled out, "I heap curses on you and yet you've come to help me. You see, my husband is up to no good. He's brought home a very young girl. I have a seven-year old son and she must be torturing him..."

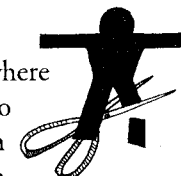
I tried to make her understand, "It is common for us paraplegics to get depressed. Our perceptions become coloured by the state we are in and we tend to interpret everything from that standpoint. Why don't you ask the doctor to call your son here so that you can check with him personally how he's treated by the other woman. Your husband did come once or twice, but how will he stay if you start ranting at him? Now when he comes, go out with him in your wheelchair and sit out in the open in the garden. You know, the sisters give me permission to sit in the moonlight, late into the night with the other women, why don't you join us? Some of the boys and girls sing. Let's try and be loving to each other, it might actually help us get better and we can leave this place soon."

Though I told her all this, I myself felt quite homesick, not at all relishing the idea of being here in Pune all alone. I wanted to go back to Kolhapur. So Ma came to Pune.

Col Watson gave her a special room to stay in. Ma started cooking and Amma and I, who both hated hospital food, began to get tasty food. The affection and love helped Amma I think, because within about ten days, she seemed to be a different person. She spoke well to her husband. She even introduced Ma and me to him and shared with us the fruits he'd bought her. And then she asked to see her son. The husband was so surprised to see this change that he got him over immediately. Soon after, her physical condition improved so remarkably that she began walking with a walker and was soon discharged. She cried when she left and kept asking me to forgive her.

And then there was this paraplegic woman whose husband, a Punjabi gentleman, who was in Pune for some training, showered so much love and care on her. That was an eye-opener too. They left together when his training was over.

I stayed four long months at the Army Hospital where I had varied experiences. When Col Singh came to know that I'd been to England to participate in the sports meet there, he felt that I should learn how to swim. But I felt shy and uncomfortable at the idea of





wearing a swimming costume and being in the pool along with all the men. It took me all of three days to decide that I was not up for it. Col Singh gave up on me as far as swimming was concerned, and thought it a better idea for me to be a functionary of the organising committee that was to organise the annual army sports meet. Now *that* was something I was only too glad to accept.

Today, I have a reputation for being a strict disciplinarian and taskmaster which quality I must have imbibed during my Pune days from Col Singh. I got into the habit of working by the clock—minutes, hours and seconds—and also doing a job thoroughly.

I can never forget the sad story of a paraplegic from Chandigarh who came to Pune for treatment. He writhed in pain all the time. He had acute urine infection due to catheter use, but before he could be treated he breathed his last right in front of my eyes. I couldn't help but remember how Col Singh had lost his temper at his colleagues the day I arrived at the hospital with bad catheter infection. Now I understood the importance of timely treatment.

Being so close to death that day brought home to me how fleeting life was. I could hardly sleep that night. Early next morning I woke up to a most distressing cry from the quadriplegic ward. "Feed us the tea," they were shouting. I realised they were shouting for help because their hands were paralysed. I felt bitter. Should such people actually be kept alive? Why are they being treated? They should just be allowed to die. I wheeled myself to their ward. I went to them, one by one, picked up their glasses and held them to their mouths. A bizarre sight for anyone who might behold—a paraplegic woman on a wheelchair feeding quadriplegics!

They felt a bit awkward about it, so I asked them, "Why, wouldn't you have helped me if I was in *your* place?"

Meanwhile my bladder had shrunk because of continuous catheter use. None of the experiments to increase its size worked. Ma stayed with me for a month and then left for Kolhapur. I just couldn't stomach the hospital food, so she made arrangements with a local family to send me my meals. Susheela, the ayah, helped me with my bath and washed my hair. She was very affectionate but there was another maid,

Mary, who was not very popular but very good with me, even bringing me some homemade food. I was lucky to encounter such affection wherever I went.

But I was baffled by the "affection" that Kedar Patil had for me. He too was a paraplegic, sad and miserable most of the time. I tried my best to understand him, chatting with him for long hours. Because of my counselling he stopped drinking and opened a cycle and scooter repair stand. Eventually, he bought a truck. But he never spent the money he made to help others even a little. Many a time I had to be firm with him when he began picking on me and finding faults with the way I ran my institute. He once told Rajni, "Oh, Naseem is arrogant about her wealth. She makes friends only with rich people." This was a bit too much and I had to end our friendship right there. Soon he started drinking again, had a heart attack and died an untimely death. Rajni and I went for his funeral. I still don't know who was responsible for his death—he himself or me.

Pune taught me many lessons on how to handle life. During that time, Babu Kaka came to nearby Vanawadi for his chemotherapy. On Sundays, whenever possible, I would get a pass issued by the hospital in order to meet him. He was the only person I could talk to about all my problems without any inhibition. He would link it up with his own experience and explain to me, "Have an open mind. Your friendships should not be based on gender, caste or any other factor. Why, you can even marry if you so desire. But don't be a victim of emotions." On my part, I could never think of getting married. My own life was such a big burden, why should I pass it on to someone else? Moreover, who can tell how a man might turn out to be? I could marry alright, and then if I turned out to be incapable, there's no stopping him from seeking another woman.

It was painful to see how Babu Kaka's body looked charred from all the chemotherapy. I would stroke his back, my eyes filling up with tears at the thought that I won't see him for too long. But he would laugh saying, "My cancer is an international guest. I can't bid him a casual goodbye; I'll have to see him off at the airport!" At other times he would say, "I've reserved my tickets, only the date needs to be filled!"

Soon, Babu Kaka was moved to the Nanavati Hospital in Mumbai during which time he needed some injections from abroad. Bhaijaan was in Dubai then. As soon as Bhaisaab informed him, he airmailed them to Mumbai while Rehana went everyday with soup for him. I was still in Pune trying my best to follow Dr Singh's instructions.

One day, he told me, "Naseema, I'm sorry, I can't do anything more, maybe I've failed. I'm afraid I can't get you to discontinue the catheter, you have no other alternative. I'm discharging you. Get your urine cultured periodically and take antibiotics regularly. If you wish to come here for treatment, inform Watson or myself. We'll be glad to make arrangements for you." Though the problem persisted, I'd gained weight and looked healthier.

I returned to Kolhapur. Everyone was glad that I looked healthy. But I was in for a shock to hear of the goings on at the Sports Committee which was set up for the Kolhapur meet. A dinner meeting had been arranged for approving the accounts but Rajani was not present. Alcohol, which was strictly prohibited, was served. And apparently, they wanted to buy a Matador van with the money that was saved in order to go to Ooty for a pleasure trip. They couldn't take out money from the bank without my signature or the treasurer's. So they used all the cash in hand. I was horrified to hear all this, so when Uncle Vasant advised me to use my rights as the President to stop this nonsense, I decided to intervene with some skillful manipulations. I won't go into the details here, but suffice to say that I managed to get the treasurer's signature on the cheque in order to return the remaining money in the Committee account to the Apang Punarvasan Sanstha.

Before I left for Pune, we had applied to the Municipal Corporation to sanction a stall for the Apang Punarvasan Sanstha at one of the shopping areas in the city. It was sanctioned in the name of the organisation, but a certain handicapped person was already using it by the time I came back. The Sanstha was paying the rent but someone else was benefiting from the stall. It was the same story with bank loans where only those working with the Sanstha got loans for starting various businesses. The loan applications of other, non-Sanstha disabled people were rotting in the files. In other

words, the institute had turned into a money spinning business! It was getting intolerable.

I'd had plenty of free time at Pune to make plans about how I should go about the rehabilitation process. I was getting more and more convinced that if rehabilitation had to be complete, it had to begin from infancy. Surgery, artificial devices, education, vocational training and even marriage—it involved everything. I prepared a questionnaire to take an accurate census of the disabled people to understand their needs.

Shivamala, Ratnamala and Kanchanmala were sisters and my close friends from school. Even our mothers resembled each other or so I thought! Their mother was so impressed with me because of how I'd organised the sports meet that she gave me some money to buy something I liked. I'd saved it and now I used it to print the questionnaire. If I had to systematically plan a project and implement it, I realised that I had to use some of my personal funds from time to time. I went personally to all the colleges, met the National Social Service (NSS) students, and formed groups for the census. And then I held a press conference. The response was tremendous. The filled-in questionnaires started coming in and I had to study them before I went any further. I fixed a date for the counting. I had got together a task force; the Sanstha was to take care only of the conveyance expenditure of volunteers. Babu Kaka suggested that I should write a proposal based on the study. I slogged over it and pumped in all my resources. After all this, the Sanstha announced, "The filled-in forms should be given to so and so and not to Naseema, since that person is educated and more capable of handling it."

"In that case," I replied, "let *him* prepare the questionnaire. I'm not handing over the one prepared by Meena Bhumkar and myself."

I had no one to guide me. I always turned to Babu Kaka, my friend and companion in these difficult situations, but how could I bother a man so ill who was going through his last days? Besides, he had to come to grips with a strike called by the newly formed union at his Bangalore workshop. I assumed that our Sanstha president would take my side after I'd exposed the obviously selfish and unethical behaviour of



its members. Not only was he indifferent, but there were seven others pitted against me. Rajani was firm, saying, "I'll do what Naseem tells me to do. I don't know anything else."

I wrote a detailed letter and sent it by registered mail to Babu Kaka at Vanawadi where he was admitted again for his chemo treatment. I wanted to visit him personally, but I just couldn't get away. I was waiting anxiously for his reply because I had withheld from informing the NSS volunteers about the outcome of the questionnaire. They were waiting too. But when I finally did hear from him, I was dumbfounded. Babu Kaka had drafted my resignation letter as member of the Apang Punarvasan Sanstha and supervisor of the training centre. He wanted me to resign! Just like that! All I needed to do was sign the letter and hand it over. But how could I do that? This was my dream, my baby, the repository of all my energies. How could I let this bunch of vultures intimidate me? But Babu Kaka wrote, "I made the mistake of trusting them and dragging you into it. They are thieves; you'll be defamed if you stay. Instead of losing heart, start something of your own. One failure doesn't mean another. Keep trying like the spider which weaves its web untiringly." I wanted no fame so how could I be "defamed?" I found it difficult to agree with him.

We had begun getting somewhere, but against all odds. District Collector Joseph got us a donation. We had also put in a proposal for a land grant.

"Get a resolution passed by the Sanstha and I'll sanction two acres of land in Shenda Park," he said.

When I put this to the Committee their decision was unanimous, "We don't want in Shenda Park, it's only for lepers."

It was clear that it was their minds that were suffering from leprosy. And now Babu Kaka was doing this to me! I was burning with anger and hurt. In fact, he called Janwadkar Kaka to know if I had indeed resigned, but he'd already left the organisation. I had little choice so I put my signature on the resignation letter.

I was almost out of my mind with anger. When it was my usual appointed hour to go to the training centre I couldn't. Now I had nowhere to go and nothing to do. It was then that I got a call from the Bank of India to take their entrance

examination. I prepared for it and did well and was called for an interview. People told me, "Naseem, the job's yours now, hundred per cent!" I was hopeful too.

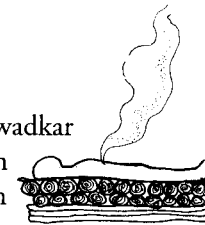
At the end of the interview I was asked, "How will you pick up the ledger and how will you come to the office?"

I promptly replied, "The peons can help me with the ledger and I can engage a helper to bring me to office."

I came home happy. They'd asked me only personal questions, not a single question on general knowledge, an area in which I was weak. There seemed little reason for me to fail the interview. I waited and waited for some news. Then, to my horror, I came to know that appointment letters had already been sent and all the vacancies filled. I didn't even get an opportunity! I thought Vijay Bhai would be able to help, so I wrote to him. He, in turn, wrote to the Bank, but was told that I'd failed the interview. I was furious but helpless. Then I got another letter from Vijay Merchant asking me if I was interested in business—cloth business; he would supply cloth from his mills at wholesale rates. But I had to *buy* the goods in the first place for which I had no money, nor did I know how to sell. So I refused that offer. Babu Kaka suggested that I become an insurance agent. But it meant a lot of movement and though my friend, Shaku Rupe helped me, you see, I had my limitations.

One day, Kausar and I were alone at home. Janwadkar Kaka called to say that Babu Kaka's condition was critical. Rajani happened to be in Belgaum for a singing assignment. I phoned her and said, "Go at once to Pune and meet Babu Kaka. I wish I could go, but there's no one at home. I'll be there as soon as Ma comes back." But Rajani, good friend that she was, came to Kolhapur late at night to take me to meet Babu Kaka. We decided to leave Kausar with a friend's grandmother.

Now I had to confront a problem head on. My catheter wasn't fixed. But it had to be done somehow since we were travelling to Pune by a state transport bus. How was I to find a doctor at this hour of the night? With Kausar's help, looking



at the mirror, I managed to fix the catheter myself. By the time we reached the bus stop it was midnight and by the time we caught the bus it was morning. As we were nearing Vanawadi, my temperature shot up and I started vomiting. Babu Kaka was worried about me even in his half-conscious state and muttered that he wished to hear Rajani sing the song, "*Keliche sukale baag*" which means "despite all the care, the banana garden is burning up."

We couldn't afford to stay in a hotel and we had no friends in Pune. So, when visiting hours were over, we decided to head back for Kolhapur, our hearts heavy and tears flowing down our cheeks. We reached at midnight, not having eaten anything since we left home. Kausar helped us put together something to eat. I was running high fever and was so exhausted that I went to sleep almost at once. The morning brought us the inevitable news—Babu Kaka had died.

I didn't cry. I just lay down, hot with fever.

I was in a daze for the next three months. I felt the same way about Babu Kaka's passing as I did when Baba died. I was no longer associated with the Apang Punarvasan Sanstha; in fact the whole experience left me disgusted. I resolved not to get involved with any such "institution" in the future. I couldn't help remembering the high enthusiasm and ideals with which I began. The cover of the sports souvenir for instance—I personally designed the cover with a picture of an eagle, wings outspread, borne high, flying towards its goal. Those wings were now brutally cut. If making money was their main goal, why for God's sake in the name of the handicapped? And more shockingly, it was disabled people themselves who were behind all this, throwing other disabled people into dark pits and making their homes on top of them. What's worse was that several intelligent, discerning and respectable townspeople stood watching as silent spectators.

One positive outcome, however, of my rushing off to Pune to see Babu Kaka was that I could now fix my catheter myself—I didn't need a doctor anymore.

One day, I received a letter from the Department of Social Welfare. There were some vacancies for posts of Lower Division Clerks in the Central Excise and Toll Tax departments. The written exam was to be held in Pune. This time I had a place

to stay with my friend Usha who had shifted to Pune after her marriage. Aziz was no longer around to take me around since he'd recently taken up a job abroad. So Parab, who used to work with Baba, accompanied me. I got through the written test and was called for the interview. At the back of my mind was the memory of my most unpleasant experience with the Bank of India. My dear friend and sole companion, the wheelchair, may once again turn out to be my enemy. I was mortally afraid of rejection, so why spend all that money to go all the way to Pune only to be rejected again? I sought out Patil Kaka for his advice. He goaded me to meet the Collector of the Excise department in Pune, a friend of Baba's. I hated the idea of pulling strings but I was fighting for justice here. I was perfectly capable of working at a desk job with my eyes, hands and intellect. Why should I be debarred from it just because I had no strength in my legs and couldn't walk? I mustered up every bit of courage I had and went with Parab to meet the Collector. I introduced myself and told him about what happened at the Bank of India.

"I need a chance to prove myself. Please give me this opportunity. If I find I'm incapable, I'll resign, I promise," I pleaded.

The Collector's tone suddenly turned serious, "You are a brave girl. I would like to have someone like you in my department. Why did you take so much trouble? A phone call would have been enough." Turning to Parab he said, "Why did you have to bother her? You could have come yourself."

There were good people in the world too, I thought, as I headed back to Kolhapur. Very soon I got an appointment letter saying, "Report to duty with a physical fitness certificate."

During my working days at the training centre, I'd kept a bed behind the partition wall. I rested there every afternoon for about an hour and a half to reduce the swelling in my legs. But here, at my new office, I was expected to work for about eight hours continuously. Besides, I had urine and bowel problems. Would the civil surgeon stamp me "unfit" for work? I had serious apprehensions. But, as it turned out, he had read about me and my work for the sports event. He said, "Why did you bother to come? I would have given you a certificate anyway. Congratulations on your new job!"



I couldn't believe my ears! A fitness certificate without a physical examination! I was on!

The first thing I noticed the next morning, were the five steps that loomed before me at the entrance to the building. Steps were a disabled person's biggest enemy. How would I negotiate them? But as luck would have it, I saw some familiar faces, faces of peons who were there since Baba's time. They hauled me up on my wheelchair. I started work that very afternoon. I was sent to the Pay Unit to work as assistant to Rehana's friend, Shakuntala Khatavkar (Rehana had worked here for three years). When I met her, a huge wave of relief flooded over me and if I had any remaining apprehensions, they vanished. Now the question was how long I would be able to sit at one go without recurring backaches and headaches. The first four months were hellish. I had sores from sitting continuously and had to rub ointments and take pills for my backache. As soon as I reached home I would lie down. Sometimes I had my dinner lying on my stomach. I would sleep at odd hours. But gradually my body got used to it.

Two other girls—Rekha Phatak and Neelima Guttikar—joined the office soon after I did. Rekha Phatak was disabled; she was a hunchback, was quite short and very weak. Neelima Guttikar was healthy, pretty and always ready to help. We made a good group.

I enjoyed working with Shakuntala. When I got my first pay cheque I was very amused—so little work and so much money! I would finish my work in no time and then help the others with their work. So I got to learn more as well as pass my time. Ma refused to accept my first salary which I handed over to her. She said, "Child, spend it any which way you want."

Meanwhile, small streams of disabled people kept coming to see me for help, though I'd left the Apanga Punarvasan Sanstha. Now, with my salary, I started helping them out with their small needs—books for some, a tube for someone's tricycle and so on. I was a bit hesitant to receive them in my office, but my colleagues were encouraging, saying, "At least see what they want. They've come all this way."

We had many flowering plants at home—rose, jasmine and amaranth. Ma picked them for my hair. Sometimes I gave away some of these flowers to my colleagues. Now, it so

happened that a certain gardener who worked at the office premises had taken over the job of hauling my wheelchair up and down the steps. He sometimes accompanied me home. Ma would give him tea and snacks. I even bought him a trouser length and a shirt piece for Diwali. But little did I know what was to come! Every morning I found a fragrant rose on my table though I never lacked for flowers at home. Since I lived close by (my other colleagues having to commute distances by bus), I was the first to see that flower. I never used it for my hair, passing it on to some woman colleague instead. It continued to appear on my table, though, day after day.

"Dear God," I thought, "what *is* this gardener up to? Perhaps I should stop taking his help and get my friends to take me home instead. I could even try going alone since my house was a stone's throw away." Even as I was working out an alternative plan, I found a letter, one day, along with the rose and then a couple of days later, another letter. My bewilderment gave way to irritation. Besides, my silence was being misinterpreted and this I discovered when I began to sense an uneasy proximity and a few extra touches on my shoulder as he wheeled my chair. I declined his help now; despite that he kept asking me if I wished to go to his village for treatment. This couldn't go on, it was time to talk to someone, but whom?

If Ma knew about this she would have asked me to quit my job. In fact, I was so irritated myself, that I even contemplated going on long leave. Finally, I chose Mane Bhausahab, who looked tough and was rather strict about things, to talk to. Besides, he liked me because I was good at my work. He said, "I'll take care of this." He started coming early to office and helped with my wheelchair. In his absence, Mr Vadar took over. They warned the gardener, "Don't you ever dare touch her wheelchair again. And let's not see you anywhere near her on her way here. If we see you, you'll not only get a sound thrashing, but you'll lose your job!" Thanks to Mane Bhausahab and Mr Vadar, I continued working.

One day, on a holiday, Her Highness Vijayadevi Ghatge of Kagal (later, I called her Aai Sahab), came home to find out more about the work I'd done with disabled people. I told her everything, including my unpleasant experiences with the

Apang Punarvasan Sanstha. She encouraged me to start all over again and offered her financial support. But I was still bitter about the experience of working formally with an organisation, so I told her that I could do something from a personal, independent position. For instance, I was more than willing to put together a team of disabled persons under the aegis of *her* Trust and get them ready to participate in the national sports competition being held in Mumbai. She agreed and we sent in a team from Kolhapur.

We bagged several prizes and Aai Saheb was very happy. She would call me once in a while and persuade me, "Start your work again, you have the potential." By then I discovered that Babu Kaka had left two thousand rupees for me in his will. He had written that I should continue with my work and begin another organisation to serve the disabled. He had made out a fixed deposit of Rs15,000 with the Commerce College so that the interest would support the scholarship of one disabled student. Janwadkar Kaka and I were the trustees of this scholarship.

Getting involved with another organisation was simply out of the question even if it was to make Babu Kaka's wishes come true. I would work independently, doing things with my own salary. I donated the two thousand rupees to the Association of the Physically Handicapped in Belgaum, a place which Babu Kaka himself had initiated. Our common friend, Shanta Phatak, was happy to accept the money. She said, "I'll take it for now, but when you start a new organisation, I'll return it." I'd always kept a small photograph of Babu Kaka as my constant source of inspiration. But now, when she asked for it, I felt that she had more right over it; after all, she was doing what Babu Kaka always wanted her to do, whereas, I had quit. When I fell ill and was admitted to hospital she would come to see me and even spend days with me. She was disabled too. She worked in the Karnataka Electricity Board where she ran a training centre for the disabled with activities like candle making, book binding, sewing and so on.

Once, Ma had to go over to her parents' because someone was ill. Our aunt, Badrunnisa Mausi came over to take care of us. A mother and son, relatives of my aunt in Hubli,

Karnataka, were also visiting. It was a holiday and Dr Sancheti from Pune was conducting a health camp in Kolhapur. I had taken a five-year old boy, the son of an acquaintance, to have him examined at the camp. I was away the entire day, from seven in the morning till seven in the evening. Kausar had an exam the next day. When I left in the morning, she wasn't looking too well, complaining of a stomachache, but since Badrunnisa Mausi was there with her, I wasn't too worried. Just take something for the pain, I said and left in a hurry. As I was clambering down from the rickshaw in the evening, I saw Mausi at the door, her face dark with tension.

"Naseem, Kausar has been vomiting since the morning. The last time she vomited, it was green and she seems to be in a lot of pain. We need to get to a doctor as soon as possible." It was a Sunday and all the clinics were closed.

"Let's put Kausar in the same rickshaw. We'll find a doctor," I said.

"No, no, I can't sit in a rickshaw," Kausar gasped, holding her belly.

So I took the rickshaw to Dr Satvekar's bungalow.

"It looks like an attack of appendicitis. My going over won't help," he said. "Get her to the hospital instead."

I went to a taxi stand in the same rickshaw, hired a cab and rushed Kausar to the Mary Wanless hospital. After admitting her, I went to Dastagir Pathan, Aziz's friend and brought him over to the hospital. Caught in all this mad scurry, I'd forgotten to empty the urine bag attached to my leg. And I also remembered that we had left the relative from Karnataka alone at home.

Kausar was already on the operation table. I couldn't see her even once. They were waiting for me to sign the consent form. I signed with trembling hands, praying, "Dear God, give *my* life to Kausar." I told Dastagir to call Rehana and Bhaisaab in Mumbai. By then I had no energy even to pray. I booked a special room and lay down quietly on the other bed, in the dark, waiting till they brought Kausar back. Every minute was a minute too long....and then, finally, Mausi's voice, "Kausar is out."

I rushed to the intensive care unit. Kausar was vomiting on account of the anesthesia. We wiped her clean but she was



restless. I couldn't bear to see her like this. Little by little, as Kausar regained consciousness, there was a string of jumbled up words, "Naseem Aapa, rest, you must be tired...Mausi had to go through so much trouble...my exams..." I thanked God she was speaking. Had we lost any more time, the appendix would have burst.

As I spent the night sitting near my half-conscious Kausar, I thought to myself, "Here I spent the whole day caring for others, but neglected my own sister. Her exams were approaching and Ma wasn't there. How could I do this to her? Dr Sancheti may have helped at least four disabled children to walk that day, but what if I had lost my sister? Could I ever forgive myself? How would I have faced Aziz whom we convinced about our confidence to manage things ourselves?" I condemned myself.

Dr Satvekar, who operated on Kausar, was an angel. He hadn't once asked if I had money for the operation. Moreover, he gave us medicines from the hospital.

The next day, an adamant Kausar, who was now fully conscious, told the doctor on duty, "I have an exam at 11 am and I want to write it." If the doctor was surprised he didn't show it. He took a moment and then said, "Okay, I'll give you a certificate, have it taken to the university and get the examiner to come here." I was horrified—it was just twelve hours after the surgery!

Everything had to be done quickly. I turned into a master organiser. I asked Mausi to look after Kausar and Dastagir was despatched to give in my leave application and his own at our respective work places. By the time the certificate was typed at the doctor's, I got ready and hired a rickshaw. I requested the rickshawala if he would be kind enough to help me fold my wheelchair. Luckily, the fellow was helpful. I even told him why I was doing all this in a hurry, looking at my watch a hundred times. He offered, "Didi, you wait right here, I'll run in and get the certificate." The hospital clerk, who didn't see the need for all this hurry, was taking his own time. So the rickshawala had a row with him, finally extricated the certificate, went to the doctor's bungalow and got it signed. By the time we reached the Shivaji Vidyapeeth it was nine.



There was a meeting going on at the Vice Chancellor's office. The peon, however, let me in when I explained the urgency. I presented the medical certificate to the person concerned.

"Just what do you think of yourself, lady?" he barked. "Do you think you can control everything? Are we your employees? You come in at the last moment and ask for favours? Is this any way to deal with things?"

I explained politely, "Sir, it was an emergency operation. You can see for yourself, the time is written on the certificate."

Now this person, who supposedly held the senior most position in the field of education, said, "Then, I'm afraid you have to pay for it. Have you got the money? Have you brought it with you?"

The stress of the previous day was now taking its toll on me. Since childhood, a sore point with me was being thought of as poor. And here was this man calling me poor and insulting me! I broke down, bursting into tears, hiding my face in my hands. Why did I have to hide my face? What wrong had I done? Who placed this man on this chair? Is education the privilege of only the wealthy? If I don't have the money, my bright and intelligent Kausar cannot write her exams. Kaushi was better than all of us in everything she did—housework, drawing, sewing, cooking and studies. She always stood first.

The rickshawala was furious. He was all set for a confrontation but I stopped him. There was no time to waste. I wiped my eyes. Suddenly, one of the professors told the Vice Chancellor that he could, in fact, locate some examiners who could make the time to go to the hospital. Relief flooded over me. I thanked him, paid up and left for the hospital.

To have a student like Kausar, seriously ill and yet wanting to take her exams, was something the VC should have been proud of. Most students drop out because they are not prepared. It was a quarter to eleven by the time I managed to reach the hospital, examiner in tow. Kausar was on a saline drip, half asleep.

"Kaushi, come on get up, wash your face, the examiner is here," I said.



She sat up slowly with the support of cushions and started writing. With the examiner's permission I lay on the other bed and fell fast asleep. In my sleep I heard Mausi's voice urging Kaushi to wake up. She too had fallen asleep and was woken up by the examiner. Kausar was given an injection after which she started writing again.

The examiner turned out to be kind and humane. I believe he must have rather admired this girl who underwent surgery just a few hours back and was now writing an exam. He called out to Dastagir who was standing outside and said something to him. Dastagir picked up Kausar's textbook that was lying in a corner and gave it to her saying, "Here, you have the examiner's permission to refer to this." The look she gave him made him put the book right back! He knew Kausar since she was a child. Everyone knew how proud and upright she was. I recalled how, (it was in Baba's time), she brought her friends home and gave them ghee and sugar though she had none left for herself. I also remembered how, when she was only a little girl in class seven, she tried to carry me up all by herself because she'd seen others do it. We were all very proud of her. Now I daren't tell her what transpired just a little while ago in the VC's room. She'd rather not have taken her exams than have her Aapa humiliated like this.

Rehana and Bhaisaab arrived at about five that evening and Ma the next day. At last there were others to relieve me. I rested for a day and went to work the next day. The rickshawala wanted to meet Kausar. He refused to take any money from us saying, "Would I have taken money from my sister if I had to do this for her?" On my own part, how could I measure what he did in terms of money? In such cases, it's better to be obliged to someone than wind up a transaction with money. In the coming months I had several occasions to use his rickshaw. I have a habit of forgetting faces, but I always remembered his. I can never forget how he helped me in a moment of crisis. When I started Helpers, he brought in many needy people in his rickshaw for whom I arranged artificial devices. I think that way I squared up my obligation to him. I have, ever since, admired him for his work with leprosy patients in Shenda Park, especially in his efforts to get them artificial devices.

Kausar passed her exams with good grades. Kausar, dear Kausar, who, faced with the most unbelievable challenges, showed fortitude like few others. I would like my readers to know what she had to go through.

Kausar's marriage to Ayaz was a case of *chat mangni pat byaha*—quick engagement, quick marriage. One day, soon after her marriage, we had a call from her. She had climbed a stool in order to clean one of the ceiling fans in her house when she lost balance and toppled down. At that point she didn't have too much pain but after some time she started feeling a tingling sensation below the waist and then the pain radiated all over her body. Exactly what happened to me! Ma and Rehana were away in Konkan, at our maternal home. There was no telephone there, so I sent them a telegram— "Kausar unwell, start back immediately." I couldn't get myself to go to office, weeping the whole day instead. My friend, Neelam Adisare, tried to calm me down, but her ministrations didn't help much. I was going mad at the thought that Kausar would turn out like *me*, a paraplegic. So much so that I had to take *four* sleeping tablets to sleep at night. Would her in-laws understand that this was not something hereditary...and then Ayaz may divorce her...what a pathetic life...etc...etc...my thoughts ran away with me. All that I'd bottled up till now came pouring out and I shared them with Ma—the gardener's stupid behaviour, Babu Kaka's absence in my life, my resignation from the Apang Punarvasan Sanstha, things bitter and sweet—I was rambling on and on, my mind in a complete whirl. I decided that there was no sense in living. There was always Tik 20, the deadly insecticide, as a last resort. (In fact, a colleague at work actually suggested I try it!) By now, my head was pounding with all the weeping. That night, I consumed everything I could lay my hands on—sleeping pills and liquids in dark bottles labeled "poison." Before doing that, I burnt all my sports certificates, my writings and other documents.

But Fate wanted me to live and the cocktail of tablets and poison didn't work; the only consequence was that I was sleepy as hell for two days and had a dreadful stomach ache which I suffered silently. No one knew that I'd tried to kill myself, indeed no one would have till date, if I hadn't chosen to write about it in this book.





Kausar had a spinal surgery similar to what I had. Thanks to the expert treatment and the unending efforts of the family and her in-laws, she began to walk.

Soon she had a son and then a sweet baby girl. Her daughter was born when Ayaz and she were living in Saudi Arabia. It seemed that they had the perfect life, happy and contented. Just before returning to India, her small family decided to go to Mecca and Medina on a pilgrimage. Ayaz was driving. All of a sudden a truck rammed into their car and Kausar, who was sitting in the back seat, was thrown out along with the little girl who was sitting on her lap. Ayaz and the son, Nadir were safe in the front seats since they were strapped in with seat belts. The car behind them stopped and picked Kausar up.

"My husband and son are in the car!" Kausar gasped and then fell unconscious.

At the hospital, she came around. Ayaz was in the intensive care unit. Nadir was too shocked to speak and the little girl was not there at all. It was all over—Ayaz's friends had conducted the burial, the sweet thing had died on the spot. Kausar was not given this piece of news immediately, she was told that the girl was seriously ill and was in the ICU. Ayaz was badly injured, totally mutilated. Aziz from Muscat and Bhaijaan from Dubai rushed to the hospital. It was three days before we got the news in India. As soon as bureaucracy allowed it, Bhaisaab arranged a passport for Ma to go to Saudi Arabia. It was sad, that she, who had never before left the shores of India, was now doing so under such tragic circumstances.

Ayaz's recovery was slow and went through the usual gradual stages of wheelchair, walker and crutches. Finally, after two whole years, he managed to stand on his feet. Kausar had turned numb like a block of stone, not opening up with anyone, even Ma. But, as I've seen, time and again, time heals and people cope. Ayaz, who now lives in Mumbai, quietly endures his physical disability with a smile and assists Helpers in many ways. Long before the accident he used to send us donations from Saudi Arabia. Kausar now tries her best to live happily in the present and forget the past. When she comes to Kolhapur, she throws her whole being into the medical camps conducted by Helpers.



Once in a while, Aai Saheb used to summon me to the Woodland Hotel where she used to stay during the time that her bungalow was under renovation. (I had first met her there when Babu Kaka took me to see her. Later she gave away that big mansion to the Zilla Parishad—District Headquarters). She served me coffee and snacks, all the while telling me of her interest in social work.



Both my brothers were now working abroad and had saved enough to buy us a house. Rajani told me that the house in which her uncle, Mr Dhopeshwarkar, lived earlier was on sale. The price, however, seemed a bit steep. Moreover, the owner offered only the house not the open land behind it. I was familiar with that house since I'd been there once to attend a haldi-kumkum ceremony conducted by Rajani's aunt. I remember loving the mango panna and the lentils mixed with raw mangoes, which was usually served on such occasions. Anyway, we decided to go and see the house once again with fresh eyes and possibly negotiate with the owner, Mrs Katre. Rehana was visiting, so she came too. Ma rarely ever left the house those days, but we both insisted that she must see the house that may one day be ours, so that made three of us. The name of the house was "Ashirwad," meaning "Blessings."

Mrs Katre received us warmly. Perhaps it was Ma's presence. She looked dignified in a white sari with the pallu over her head. Mrs Katre must have been impressed with Ma for she was most respectful. The house was located near the Central Excise Office and there were only *three* steps leading into it! (Disabled people always notice steps). She showed us around the entire house. Rehana made things clear, "Both our brothers are abroad. So the deal has to be clinched on paper, not with cash." That seemed acceptable to the lady. There was a built up area of 1000 sq. feet and the total land measured 11, 000 sq. feet. We made an offer of about three and a half lakhs and she said without any ado, "Agreed. I give the bungalow and the surrounding land to you. But you will have to complete the paperwork with my son, who works in the police department in Mumbai." That suited us too, since Bhaisaab, who looked after such matters in the absence of both my brothers, lived in Mumbai. He was running his own business now after his stint at the Embassy of Iraq.



As all this was happening, I recalled the big debates around Aziz taking up a job abroad. Many people close to us felt that since I was disabled, the family needed the presence of a male member. But I was adamant, saying that Aziz's future should not take a back seat on account of me. Aziz had graduated shortly after Baba's death. It was difficult for him to get a job here, leave alone a *good* job. The prospect of my being a burden on anyone was most distasteful to me and anyway, Aziz would always help me, as I'd discovered during my tenure at the Sanstha. He was in a fix, caught in the crossfire of dissent. But I encouraged him to go saying that with the good salary he would get, he could get us the many things we needed. Our elder brother, Bhaijaan was married and he was in Dubai with our sister-in-law. He came to India once every two years. Aziz was offered a decent, well-paying job and besides, he could come home every six months on company's account.

Aziz's new job could support some of our expenses. My ailments were life threatening and treatment was expensive and though Bhaisaab helped us financially, Aziz's contribution was most helpful. It was only because he went abroad that both our brothers together are able to buy us this house today.

Mrs Katre's voice shook me from my reverie. "My husband made this house with the greatest enthusiasm after his retirement but he didn't live long enough to enjoy it," she said, her voice sad. "When I see your mother now, I feel assured that the house is in good hands." After all that we had heard about Mrs Katre's terms, this came as a surprise. We'd heard that to the world at large, she had quoted a price for the house which was, in fact, higher than that which she was now quoting for the house and land combined.

The paperwork was smooth. Before we shifted in, we had some specific requirements though. My wheelchair had to pass through all the doors and the toilets should be convenient for me. My brothers' savings were exhausted just buying the house and so we had to go slow. Four doors had to be widened, the wall in my room had to be broken down to make it bigger, and a slope and railing had to be constructed near the steps at the entrance. It took us one year to finish all this work. In 1980, laden with everyone's

blessings we shifted to "Nasheman." I never missed Baba as much as I did then. I remembered his favourite song, "*Ek bangala bane nyara*." This song, from a Hindi film, was sung by the legendary K L Saigal voicing the wistful longing of a man who wanted to own a beautiful bungalow. Had Baba been alive today, he would have actually experienced the thrill of owning his own little bungalow.

Soon after we shifted in, Mrs Katre came over to see us. She was overjoyed to see her garden in full bloom with roses, moria and jasmine. The fruit trees had papayas, chikkooos, mangoes and guavas.

"I knew that this place, so sacred to me and my husband, would remain so in your hands. I'm glad I sold the house to *you* without bothering too much about the money," she said, clearly satisfied with her decision. She had tea with us.

"Nasheman"—many people including our postman thought that the house was named after me.

"Oh to have such brothers! They love their sister so much that they've named the house after her! Naseem is fortunate!" people said. "Naseem" means "early morning breeze" and "Nasheman" means a "small house." Even though the two words had completely different meanings, they were convinced of my brothers' boundless love for their sister! Not just my brothers, Baba loved me too. My birthday falls on September 2, one day after payday. And, though it was not customary for us to celebrate birthdays, Baba always got home some special sweets.

One day, Aai Saheb came to Nasheman with her daughter-in-law, Suhasini Vikramsinha Ghatge. She introduced me saying, "This is Naseema. She has a great interest in social work just as I do. I was suggesting that we start an institute, the three of us, along with Rajani."

"*Institute*." When I hear that word, memories of my bitter experiences with the Apang Punarvasan Sanstha come surging up. "I haven't yet decided whether I should work with a formal institution. Give me some time to think."

A large number of disabled people continued to visit me. I recalled the corruption that went on at the Sanstha. For instance, we had acquired a tricycle from NASEOH, Mumbai. But instead of handing it over to a poor, needy,

disabled person, the tricycle was used by some of the disabled staff in the organisation. It was clear that they were not in the business of helping anyone. And after all, how much could I do on my personal salary? Also, I hadn't quite forgotten Babu Kaka's wish that I should start an organisation on my own. All these seemed to be good reasons to give the idea some serious thought.

One day, the four of us sat together to discuss. We decided to begin our work with children. As a first step, we sent a letter to each school in Kolhapur asking them to make a list of disabled children. When we got the list, we called a camp for the disabled children along with their parents. We made a fact sheet and noted down the actual requirement of each child. Then we made an expense estimate to meet those requirements. Right from the beginning, I was of the opinion that we would not formally register any institution till we had a trial run of our work, unlike the Apanga Punarvasan Sanstha which first raised hopes then brought them crashing down. That suggestion appealed to everyone including Aai Saheb.

Some of the mothers had to physically carry their children to school. We needed two wheelchairs and three tricycles immediately. But where was the money to come from? We arranged for it with our personal contributions and ordered a wheelchair from Mumbai for one of the boys. I took the wheelchair to the boy's house only to find out that he had died eight days ago! The mother was grief-stricken. That was our first lesson— we would never hold a camp till we were hundred per cent ready to meet the needs of the people.

During our first year, we helped poor disabled children by distributing artificial devices, school materials, school fees etc. Then we met Mr Kadam quite by chance. He was a Traffic Police Inspector who got interested in our work. He suggested a unique plan to raise funds. There was a law that every vehicle that plied on the roads should blacken half their headlights as a traffic safety measure. During the summer holidays I took leave of absence from my office. Two or three of my colleagues joined me. Then we supplied the disabled children from our first camp with black paint and brushes and they started painting the headlights right there, under the bright sun. We would then request drivers

to drop the small fee for the painting in our box. The police helped us with this. The kids had fun and they also liked the idea that the money collected was to be used to buy tricycles for disabled school students. We collected enough to buy three tricycles which were distributed by Aai Saheb. Thus, a simple idea conceived by Kadam Saheb worked.

Every now and then, however, I would suffer from catheter infection. All of a sudden, I would shiver with fever. It would go up to 104, 105 or even 106 degrees centigrade. Dr Satvekar would admit me in hospital. Once I had to get an Intra Venous Pyelography, a procedure to examine the small intestines. Aziz was home on leave. He tried explaining to Dr Sushil that mine was not a routine case and needed urgent attention. But the doctor was short with him, "You seem to be an educated man. I'm surprised that I have to explain these things to you in such detail!"

Aziz was furious, "My sister is paraplegic! She has serious bowel problems and needs an urgent X-Ray. Or should I take her to the military hospital in Pune just for this?"

The doctor's harsh exterior seemed to soften. "I'm sorry. Bring her. I'll make all the arrangements." The next day he treated me not only with affection but also with a certain sensitivity so that I wouldn't feel awkward. And finally, when Aziz paid the bill, Dr Sushil put the entire amount in an envelope and placed it in my hand. He said, "I know all about your work. I took the money from your brother so that he may always remember his duties towards his sister. But here, take it back and use it well."

"No, no, please accept it," I tried to return the money. "I have a job, my brother pays for my medicines and since I'm not associated with the Apang Punarvasan Sanstha, I can't give the money to them."

"In that case, do whatever you want with it, but don't give it back to your brother!" he joked. I put away the envelope without opening it.

I had an opportunity to use that money later to buy white uniforms for a team of students who were being sent to Mumbai for a sports meet. We invited Dr Sushil and his wife to the station to see the team off and to wish them good luck. Since I couldn't get leave from my office to go to Mumbai, an



older disabled boy was deputed to be the team manager. He had already been given enough money for expenses, yet he embarrassed us all at the train station by asking for more money in front of the doctor. Just a little while ago, I had given whatever I had in my purse to those who were going to Mumbai for the first time and who had no pocket money. So I was broke and had no money even to take a rickshaw home. I had no alternative but to ask my friend and colleague, Rekha Phatak who accompanied me, for a loan. But the doctor heard us talk. "Should I give you some money?" he asked. We had little choice. "I'll return it when I get my salary," I said holding out my hand. I felt awkward and embarrassed. What would his wife feel? That we invited him to the station just to relieve him of his money? The doctor took out his wallet and put all the money in my hand without even counting it. I was stunned by his generosity. I gave some of it to the team manager and put away the rest of it in my bag. As soon I reached home I made a note in my diary.

My expenditure exceeded my salary. I wasn't able to deposit more than hundred rupees in the General Provident Fund of the office. I borrowed from Ma. I hated doing this, but there was always someone in more need of money than I.

Rajani scolded me, "You have a job but you don't contribute a single paisa towards household expenses. On the other hand you *borrow* from your mother. Most improper, I tell you!"

It took me several months to return the money to Dr Sushil. One day, I went to his place, money in hand. He took it without saying anything, without his open smile. I told myself, "I'm sure he's disgusted with me, asking for money at the station and then taking so long to return it." After that, for several years, I could not bring myself to meet him. I'd fallen in his eyes, I'd lost his confidence. I had even sent him a letter saying how sorry I was for what I did, but there was no reply. Many years later, when I had occasion to go to him for the sake of a beneficiary, I plucked up courage and blurted, "It seems that you have an issue with me about that money. Please tell me what you feel."

He said, "I never did want it back, in fact, it never crossed my mind when I gave you the money. I was most unhappy

when you returned it. I told my wife, 'That lady has a lot of self-respect. She doesn't like to be helped.'"

I said hastily, "No, no that's not true, I have no problems about taking money from people, in fact, Helpers is wholly dependant on peoples' financial assistance! Why didn't you tell me this before?"

He started coming to Helpers and attended our events. I felt relieved at last. Now he donates money to us occasionally.

I enjoyed my job. When I finished my work, I used to chip in and do the work assigned to other people so that soon I was familiar with the work of each department. What I learnt then serves me well today as I run my own organisation. Back then, I was given the additional responsibility of doing someone else's work if that person went on leave. It appeared that I could do both jobs well, theirs and mine. My work was appreciated by my supervisors, Mr Khanolkar and Mr Gaokar. Then one day, a new Administrative Officer took over. He started putting colleagues on duties which were not part of office work and then made *me* responsible for their work. So far, so good. But then I fell ill and got hospitalised. When I resumed work, I was asked to explain in writing why a *colleague's* work was pending for so many months! Why was *he* not held accountable? This was injustice, plain and simple and I couldn't stomach it. I went to see the Assistant Collector (Central Excise) with the papers as proof. He called the Administrative Officer in and issued a warning. Now, it so happened that the Assistant Collector lived upstairs. After I was discharged from the hospital, he used to see me on Sundays finishing off the "pending work." He used to ask me, "Why have you come alone? Why isn't the Administrative Officer also here?"

It was during my second or third year in the job that Mr Gaokar was appointed Administrative Officer. Every year, there was a brouhaha about the annual budget prepared by the accounts department. I offered to help. They kept fobbing me off saying, "Forget it, you can't handle it, you're new here." But Gaokar Saheb called me to his office, put the file in my hand, saying, "Study this thoroughly. Go on, prepare this year's budget. Check with me if you have a problem." I was quite excited because here was something that I wanted to do



all along! I began in earnest and found that there was not much that I couldn't handle barring one or two small queries which I cross-checked with the boss. The budget was ready, and much before time! After that, I prepared the budget for several years. Gaokar Saheb gave me a certificate of acknowledgement.

Soon Mr Jitendra a young man, took over as Assistant Collector. He read my report on stocktaking and wrote "Very good, keep it up!" on the paper. What a great feeling to be appreciated thus!

I have had my share of "unpleasant" experiences with men. My brothers often got me spray perfumes from abroad so that any odour caused by my incontinence or bowel problems got camouflaged. Rehana's husband had found very good jobs abroad for both my brothers and they earned well. I had several imported saris as well. The men began to notice my perfumes and saris. I felt embarrassed and gave away most of my pretty saris. I went slow on the perfume and began wearing white. My friends couldn't understand why and told Ma, "What's wrong with Naseem? Has she turned into a nun?" I switched over to cotton and then I began getting gifts of pretty cotton saris for which I got profuse compliments from the men. An able bodied, married man went to the extent of writing a love letter to me describing me in white saris. He was eager to have a second marriage and I was the most suitable candidate! One disabled Bengali fellow expressed his wishes quite decently and even when I declined, he asked me smiling, "Shall we be still be friends?" We became pen friends. A polio-affected Gujarati Muslim also proposed marriage. I conveyed my regrets politely and suggested a suitable girl for him. I gave her some money from my salary and sent her to Gujarat to get married. They were so grateful to me for arranging the match that their first daughter's name was an anagram of mine!

But I confess to having shed tears for a young Maharashtrian boy whose feelings I reciprocated and who I declined because I didn't want to spoil his life. Till date, I don't regret that decision. Besides, I was totally committed to the work that Babu Kaka had passed on to me; marriage and children would only be obstacles. I was also privy to the lives of several of my

women friends whose lives had been wrecked because of men who turned out to be narrow minded and suspicious. All this made me cautious.

Rekha, Neelima and I gave all the mandatory exams that would elevate us from Lower Division Clerks to Upper Division Clerks. We did well and passed in all of them. Both of them were ready to accept postings to other places but I refused. We were due for a promotion in six months, and some others were due for new postings. So a union meeting was convened. We heard comments like, "Hmmm...they come *this* way as Lower Division Clerks and go out *that* way as Administrative Officers." I never knew what it meant or what happened later, all I knew was that we never got any promotion orders.

I remember an incident that occurred eight or ten days after this meeting which I can never forget.

It was one of those days when my infection gave me a severe headache which persisted despite having taken a pill. Shakuntala Kharavkar was out of the office. I was in such discomfort that I put my head on the table. Just then a colleague, (who would have got transfer orders if I was promoted), asked me, "Why have you got your head down? What's the problem?"

"I have a severe headache," I replied.

"Take some Tik 20, it's a *permanent* cure," he suggested. I was aghast! He was suggesting that I take poison and die! Was I so unwanted? If it was a joke, what kind of joke was it?

"No shopkeeper will give it to me. Could you get it for me? I'll feel grateful," I said quietly.

I was so upset that I wanted to go on leave but I refused to "entertain" my immediate boss with tea in order to get it sanctioned. (He was the same gentleman who once told me while sanctioning my pay raise, "You have to put some 'weight' on the application.") I was totally new to this kind of language. Innocently, I sent him my paperweight through a peon. Naturally, I became the butt of laughter till someone made me understand what it meant. The "weight" meant a bribe.

I asked my boss, "Sir, don't we all, including you, get paid for our work? Is it not totally unethical to accept anything over and above that?" He made a quick exit and like a fool, I started crying. When Shakuntala came back I told her

everything. She consoled me, told the senior officer what happened and took me home.

Back home, the fever rose dangerously, so it was hospital again for a few days, antibiotics and injections day and night. When I look back, I see how it was almost customary for me to get hospitalised for one thing or another two or three times every year for a course of medicines. The medicines gave me an awful stomach ache and I just couldn't eat. So they put a tube up my nose. The constant nasal feeding irritated my throat, so much so that one day, I pushed away both the nurse and the tube in anger, saying, "Go away! I won't let you put in the tube even if I die!"

But luckily for me, Dr Satvekar understood that the anger came out of my helplessness and treated me with the greatest affection, never getting upset with me even once. The sisters complained bitterly about my frequently soiled sheets and poor Ma was subject to this constant litany of grievance. Finally, with the doctor's permission, we brought sheets from home which we took back. Gradually, the hospital staff started behaving better with me perhaps because, one day, I confronted them outright, "Why take up a profession like nursing if taking care of patients is too much for you? There are hundreds of jobs available. Don't bother with me, thanks, my folks will look after me. But the least you can do is be civil." Sister Malekar was the only exception.

Though I was bedridden and was on my back twenty-four hours, I kept my hands busy making crochet doilies. Suddenly I had so many that I began gifting them to the sisters. One day, I had a flash of a thought, "Why not *sell* them and make some money for crutches or school fees or whatever, for disabled people?" Since then, whenever I couldn't sleep, I refused to take sleeping pills, and took up doily making with missionary zeal instead. Ma scolded me, saying, "Stop this now and get to sleep." However, her most recent fear was caused by my blurred speech because of my heavy tongue thanks to all those sleeping pills. She kept thinking, "Oh God, will she go *mute* now?" So she was happy that instead of taking those pills I sat up all night crocheting. My doilies sold quickly.

Aziz got married and twenty-year-old Irshad joined the family. Once, when we were all sitting together, her parents

told her, "Take good care of this sister-in-law and win the heart of the family."

But I was appalled and told Ma and Aziz, "No indeed she will *not*! Aziz should move into a separate house after his marriage. Ma, you will make this poor girl, an outsider, do work for me, and if she shows any reluctance, you're bound to get upset."

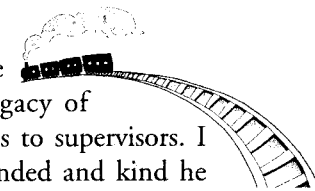
Aziz had only one thing to say, "Then I don't wish to marry."

I had been toying with the idea of living on my own. Before I got a job, I had expressed my wish to go to Anandvan to stay with Baba Amte. Ma was hurt, "How can you talk of leaving home? Over my dead body!" And that was that.

Irshad's first birthday after her marriage was celebrated in my room at the Mary Wanless hospital where I was admitted. There is no room or ward in that hospital where I've not stayed some time or other. Everyone knew me and they were all fond of me.

I always remember a few people every time I get admitted there. One was Sister Malap who worked at the Chhatrapati Pramiliaraje Rugnalaya Civil Hospital (CPR). She had a small baby, still, after her duty hours, she went home, finished her cooking and at night came to my place to give me an injection. She was always gentle and polite and never took a paisa from me. Dr Satvekar too refused to take any money from me till I got a job and that too only because I insisted.

I had good experiences at my workplace thanks to Baba. He had left behind a legacy of cordial relations with everyone—from peons to supervisors. I kept hearing from everyone how broad minded and kind he was. Once, he had even gone to the extent of helping someone by borrowing from his own provident fund. The staff always offered me a hand, whether it was washing my lunch box or getting water or tea for me. We were a group of about ten or twelve people who ate lunch together, sharing the different types of food which we got from our homes. My home was the closest to the office, so I got hot masala bhaat or phodnichha bhaat with bhajyanchi kadhi, which was seasoned rice with



pakoda curry. Some of us were fond of biryani, mutton and fish, so I got larger quantities of these sent from our home.

But I could never understand why many of us, instead of looking happy on pay day, looked desperately worried. As our boss, Gaokar Saheb was wonderful. He literally drove us out of the office on pay day, saying, "Go on, get out, go for a movie, do some shopping, enjoy yourselves today. Work can wait till tomorrow." I thought every office should have someone like him. That's why I was surprised to see so many sad faces on salary day. So I began digging a little to find out why. I learnt it was because they had borrowed from the office on account of some illness or wedding or whatever at a very high rate of interest—ten per cent every month. For several years they had been paying off just the interest, the capital still remained to be paid. So the salary was insufficient and they borrowed again. It went on and on—an endless cycle of borrowing. I felt I had to do something, so I kept aside a part of my salary to lend money to some of my colleagues.

We had a special Diwali fund. We contributed to it every month and when Diwali came we received the amount back with interest. In case someone needed to borrow from this fund prematurely, he could, at an interest rate of two per cent per month. This interest was distributed among the contributors.

I had been thinking up a plan to relieve my colleagues from the debt trap, so I started a scheme—a Staff Welfare Fund. The rules were as follows: everyone should contribute to this fund as per their own convenience. We could lend from this collection at an interest rate of Rs1 per month. The amount collected by way of this interest would be distributed to all. When someone retired or got transferred, he would get back his contribution. Those who were burdened with debt right now, could borrow from this fund in order to repay their high interest loans so that they were able to keep their salaries for themselves. I got unanimous approval for this scheme and ended up managing this fund for about fourteen years. My colleagues not only cleared their debts, but also managed to meet their other domestic needs like TVs, washing machines, furniture, hospital bills, marriage expenses and so on. All this at less interest rates. During my tenure

there were instances when some of the members borrowed from the fund only to slyly lend the money to others at a higher rate of interest. I closed their accounts immediately. I had no inclination to pardon such irregularities.

Whenever I fell ill or my work with disabled people disrupted my routine, I asked my colleagues to help me which they willingly did. But, unfortunately, when I decided to retire, we had to close the accounts and refund the amount to contributors because no one was willing to take up the responsibility.

Since I was in charge of the Staff Welfare Fund, I was also the Treasurer of the Central Excise Recreation Club for several years. It was only when the work of Helpers took a lot of my time that I gradually started to distance myself from activities such as these. But I really did have a lot of fun organising send-off parties, planning menus and seating arrangements with a small team of willing colleagues.

Though I'd grown very close to all my colleagues, I was still sore about the earlier incidents regarding my promotions or even the Tik 20 advice from the "well-meaning" colleague. As a result, I was too overwhelmed and intimidated to take any upper grade exams. I decided to remain a Lower Division Clerk forever. Whatever my designation, I was able to handle any assignment, even that of the Administrative Officer if required, except of course, putting his signature to a document. Gaokar Saheb noticed that even those who joined after me were getting promotions but I remained where I was. One day he called me to his office and asked me the reason why. He said, "If going to Pune for the exams is a problem, I'll help you."

I had to tell him then, "Sir, the fact is that even if I do get a promotion, I still won't be able to leave Kolhapur because of my condition. So, the others who get transfer orders after their promotions would hold it against me."

"Well, we'll see about that later," he said. At first he tried to explain, then scolded me and literally forced me to go to Pune. He gave me some tips. But I was already used to referring to the departmental books in order to do a lot of the office work. So I found those tests where I could refer to books quite easy. I stood first in all the papers but was too excited to tell

Gaokar Saheb. The credit goes entirely to him; it was because of that exam that I got all my subsequent promotions.

Now my colleagues decided that I should be given a "promotion party" in our office clubroom. The volunteers of Helpers helped along with my colleagues, from cooking to serving. Interestingly, each time, my promotion orders came to me when I was hospitalised! My colleagues brought the various orders to the hospital. In fact, I was even given my salaries there. Many of them visited me with homemade food of my choice and once I was driven straight to the hospital from work and Ma was summoned later.

During that time I donated blood regularly. When the blood bank was not short-staffed, they sent them to our workplace to take blood, otherwise, my colleagues and I went to the blood bank ourselves. There were very few donors then. Once I got a phone call from the blood bank. It turned out that the Assistant Collector's mother needed a transfusion. Our boss, Mr Pai, who was visiting the lady, was surprised to see me there. I don't know what Dr Sulgaokar and Dr Divekar from the blood bank told him, but Pai Saheb was very impressed with me. He has retired many years since, but even today, on his birthday and other occasions, he donates large amounts of money to Helpers. Once, as a response to an urgent requirement of blood at CPR, I rushed there and was the first to donate. I felt so happy that I'd helped an unknown patient.

Like all of us, I was once confronted with a dilemma. I couldn't talk about it with Ma or with friends. So I decided to speak to Pai Saheb who was like my father.

It was about a young girl who had no father and whose mother was ill. She had no education and no job. She sold vegetables for a living but that hardly sufficed. So she had to earn some extra rupees and got into prostitution. But she was not a regular, doing sex work only when the need was really acute. Some men kept using her services and didn't pay. She knew me because of my work which was reported often in newspapers. I also happened to know some of those men who cheated her, so she came to see me. I was aghast when she told me about her poverty-steeped and sordid life. I asked her, "Will you do *any* work I give you?" She nodded between sobs. So without disclosing details of her past to anyone, I employed

her as my helper, assuming that she would regain her dignity when she was seen around with me doing a so-called "respectable" job. I turned out to be right. She travelled with me on many of my tours. Later, she married a widower who had a child. I've lost touch with her since, but I hope she's happy, wherever she is.

Rekha Pathak and I became very close friends during the first five years of our working life. When she died there was a void in my life. During the last few months of her life, she was like a stuck record, going on and on, "I'm not going to live long, but before I die, I want to see the Taj Mahal. My folks won't let me go alone. Come on, Naseem, you're quite adventurous, let's go, we might have some problems, but so what?" This went on every two or three days. On Sundays, whenever she was bored she came to see me. We used to loaf around in a rickshaw, doing some shopping, eating out. The rickshaw driver was also included in all of it. She helped me with my shopping, running in and out of shops while I waited.

When I teased her about her frenzy she said, "I'm not going to live long."

"Ha, ha, who will let you go alone? We'll go together if we must!" I joked.

Each time she spoke of death, I thought she was joking because she always had a smile. But one day, her eyes clouded over with tears.

"You don't believe me, do you? You'll regret it when it becomes a reality. Memories of me will haunt you if ever you go to Agra to see the Taj after my death."

She had such an overwhelming intuition that her life was going to be short that she refused to marry her childhood sweetheart. In fact she was ill in bed on the day of his marriage to another woman. When I saw how distressed she was, I decided that I *must* plan a trip. I told my folks at home that Rekha, a few other friends and myself would be going to Delhi. We roped in Rajani, Shanta and David (President of the institute in Belgaum). We were a strange, motley group of enthusiasts with either one leg or no legs! Kedar Patil from the paraplegic home in Pune wanted to join us too.

We knew no one in Delhi. Rekha had an address for an organisation called The Institute for the Welfare of the



Handicapped. We wrote to them immediately with a request—"Kindly make arrangements for eight people—five disabled (which includes three on wheelchairs and two affected by polio) and three assistants." When they confirmed accommodation, we booked our train tickets on the Pashim Express from Mumbai bound for Delhi. On our return, we were going to stay with a friend in Baroda. It was the month of March 1980. We decided that since we were going that far, we would visit Agra, Chandigarh, Jaipur, Mathura, Bhakra Nangal and Baroda. Preparations, therefore, had to be exhaustive.

In Delhi (following Babu Kaka's example), we decided to meet with Prime Minister Morarji Desai. David was to take the file that contained all the correspondence regarding the land application for their institute in Belgaum. Also, though I wasn't associated with the Apang Punarvasan Sanstha any more, I told the Secretary that we were going to see the Prime Minister in Delhi and I could put forward *their* application as well but I didn't get the file till the last minute. I packed in the typewriter which Bhaisaab and Aziz had given me, as well as a first aid kit, screwdriver, a pair of scissors, knife, clothes and curtains for private partitions. We were ready, finally! Our families came to see us off and bid us farewell with plenty of good wishes.

We were stocked with goodies to eat so there was plenty for dinner. But we had no idea what was in store for us. At Kalyan station, we got some disastrous news—the train that was supposed to proceed and terminate at Dadar was to halt right there. We were stupefied! It was perfectly easy for people to disembark and board another train, but for the likes of us...that's another story. Rehana and Bhaisaab were waiting for us—the wheelchair brigade—at Dadar station in order to take us to Bombay Central to change trains. Uncle Haroon Khan, who lived in Kalyan and who had come to the station to see us, arranged an announcement over the public address system that we should board the Simhagad Express for Dadar. Easier said than done! Where was the time! Fortunately, the ticket conductor and the train guard at Kalyan were most helpful, detaining the Simhagad Express just for us. The next few minutes passed by in a whirl of action-packed frenzy—how we disembarked at Dadar, transferred ourselves into taxis

and reached Bombay Central—I just didn't know how. I just knew that three taxis were ready for us at Dadar. There were only fifteen minutes left for the Paschim Express to depart. When we finally made it to our compartment, we found that our seats, (reserved over a month ago), were occupied by others. They flashed their tickets at us triumphantly. Just then, someone told us that another coach had been added to the train so we rushed there. My uncle objected but I stuck to what was my motto and stands me in good stead even today—not to turn back once I get started and never to fall back on my word. I told Prakash, David's helper, to lift me and put me on the train. Rekha clambered in and then Rajani, then all the others. We heard the whistle. Bhaisaab, who was stunned beyond words, asked me, "Naseem, what on earth should I tell your mother and sister?"

Instead of answering him I said, "Our tickets are with you. Give them to me before we get into more trouble!" He thrust the tickets into my hands as the train chugged out.

The train caught up speed and all hell broke loose. Much commotion amidst, "This is a ladies' compartment, why are these *men* sitting here?" The ticket conductor arrived on the scene.

"If the men are upsetting you so much, why don't you file a case against them?" he asked sarcastically.

I said, "In fact, we should be filing a case against *you* for harassment despite having reserved seats booked over a month ago! How can *two* people book themselves on the same berth?" There was nothing more he could say and he shuffled off. To top it all, the women in the compartment made our helpers (who were all male) leave their seats.

Our luggage was in a mess. A bag that was kept on a shelf above Rajani's seat fell on her nose and it started bleeding. We weren't able to eat our breakfast because the compartment was so crowded that we couldn't lay our hands on our tiffin boxes so lovingly packed by Rehana and given to us in Mumbai. We couldn't fill our water bottles either because of all the rush. The train hardly stopped long enough at stations to fill them, so we had to buy water at the window. As we neared Delhi it began to get terribly cold, but it was impossible to take out our shawls and blankets. It was



midnight and our helpers were tired standing up all the time. So Rajani and the others sat on the edge of their berths while they slept behind them. The night police were on their rounds. One of them asked us who was sleeping behind us.

"Oh, it's one of the women," said Rajani. The train was shaking violently and it was cold, so the helper adjusted his sheet and to our horror, a pair of feet, *male* feet, stuck out from under it!

"Aha! A man!" said the policeman and started shaking him awake, hurling remonstrations at Rajani.

She said, "What can we do in this situation other than tell a lie? We disabled people have to take more care of our *helpers* than ourselves. It's only because of them that we have undertaken such a long journey."

But the policeman was being bloody minded and began to rough up the helpers. Our fellow women travelers joined him by proclaiming their displeasure in having their compartment invaded by men. I was watching silently, rather amused at what was happening. Finally, I said, most politely to the policeman addressing him as "dear brother," "Bhaijaan, it's okay, get rid of our helpers. But as you can see, we are disabled. When we need to go to the toilet it's up to *you and these ladies* to decide who will help us." That did it. The policeman left and soon the crowd thinned down. To our utter consternation, a couple of women unfolded our wheelchairs and sat themselves down most comfortably. Now that's a great idea, why didn't we think of it!

I was apprehensive all the way to Delhi, not knowing whether we would reach there alive. Every part of my body ached. Rekha's friend in Delhi received us at the station and took us to where we were supposed to stay. We were taken to the office where we saw one folding cot and several tables, chairs and cabinets piled up with blankets. There were some mattresses too. "*Alia bhogasi asave sadara*"—accept what you get, I thought to myself. After our near death experience, we were lucky just to have a roof over our heads. We had our bath and ate something—finally we were all feeling fresh. The President of the Handicapped Welfare Institute, Gautam Khanna, and the Secretary, Sandeep Sood treated us warmly. Khanna used a wheelchair and Sood used crutches. Both of

them were married. They invited us for meals to their homes. We told them that one of the things we wanted to do was meet the Prime Minister so they got us an appointment.

David, Shanta and I spent the night preparing the papers. Our appointment was for quite early in the day, so we planned on a sightseeing trip afterwards. The PM welcomed us warmly and listened to our problems patiently. He glanced over our application, gave it to his secretary and ordered him to take care of it immediately. Weren't we surprised when we discovered that the land sanction letter had reached Belgaum even before our return!

Janwadkar Kaka had given us travellers cheques so that we didn't have to carry cash with us. So each time we needed money, we had to sign one of the cheques and go to the bank to have it encashed. I told Rajani to handle this.

She said, "Naseem, my signature keeps changing each time I sign. So it's not going to tally and the bank is going to raise objections. Why don't you do it?"

I told her, "No my dear, I'm afraid I can't. I have too many things to take care of. *You* must do it." So she trundled off to the bank while we waited in a restaurant. But she was taking the longest time to return. In the meantime, we wanted to have hot coffee to warm ourselves. But it turned out to be so expensive and we had no cash. Moral of the story—people like us should never bite the travellers-cheque bait! We should always carry some cash. That's free advice from me.

We engaged two taxis and charted out an itinerary of sightseeing stops. The two taxis started out at the same time and we were to meet at every stop. But our drivers were so enterprising that the two taxis met at the Institute premises only late in the evening. We missed having our tandoori lunch together as we'd planned. We asked people—at India Gate, Qutub Minar, Lal Quila, everywhere. Always the same answer, "Yes, a small group of people on wheelchairs, just like you, were here about half an hour ago."

That night we gathered in the moonlight with the other members of the Institute. They invited us to take part in the World Disabled Day sports meet. Rajani was clearly the star with her wonderful singing. We saw a beautiful painting by



Mr Pardeshi who painted with his one left hand and we made a new friend, Premila.

The next day we left for Agra and this time, the two taxis stayed together. Finally we were seeing the Taj by moonlight! Our collective dreams had come true. Our helpers had a tough time trying to lift us, along with wheelchairs, up the innumerable steps, though the taxi drivers volunteered to help, giving us a ready hand. Like Rekha, we all wanted to see the Taj at least once in our lifetime. It so happened that I was to see the Taj again several times on my many trips with the inmates of Helpers. But the moonlight, ah, that's another story. I can't put it in words! We were so overwhelmed that we sat in silent awe for quite a while. Rekha was particularly thrilled. Thanks to her we were here. On our way back, we stopped at the Shri Krishna temple in Mathura.

We were ready for the next leg of our journey. Armed with a letter from Col Singh introducing us to the paraplegic home in Chandigarh, we packed up and were ready to leave early morning. The taxis were waiting. But it turned out that Rekha had high fever and was shivering. It was during this trip that I realised, for the first time, that Rekha's disability was more tortuous than ours. She had a hunch on her back which made it very difficult for her to sleep on a bed. Her heart, which had an unusual shape, was situated on her right side, making it very difficult for her to breathe if she lay straight. She spent whole nights sitting with her head on a pillow, *never* really able to get a good night's sleep. I felt personally responsible for Rekha and suggested that I would stay back in Delhi with her while the others would carry on as planned without losing too much time. But they didn't want me to stay back, at the same time it was too risky to take Rekha with us. She couldn't breathe and the fever was raging. What to do? Kedar Patil, who got to know her well on this trip, finally said, "All of you, carry on. I don't mind staying back." And that's what he did. We left most reluctantly.

Chandigarh was a feast for our eyes. The rose gardens were in full bloom, the paraplegic home was big and spacious and the Bhakra Nangal Dam, the second biggest dam in the world, was awesome. But we thought of Rekha and Kedar every minute.

So far, as wheelchairs go, only Babu Kaka's had ever reached the dam site. Ours were the next. The staff working on the dam site still remembered his open smile. People were kind to us everywhere.

The destitute girl, Sukumar, living with Laxmibai Jadhav, who worked at the Training Centre of the Apang Punarvasan Sanstha, was my helper on this trip. Though it was pretty cold at that time of year, she never drank hot tea or coffee, so I gave her hot milk instead. It was important that she stayed healthy else it would be miserable for me to travel. I paid for all her expenses, plus daily wages. She was mentally challenged and therefore a bit slow, but she did everything assigned to her, including the laundry. I don't know if I was, but I was accused of being a bit over-caring about her and perhaps I was. But I was the tour leader and I had to make sure that *everyone* was well taken care of. Discipline had to be enforced as well, and I became quite unpopular because I had the nasty job of waking people in the morning.

We came straight back to Delhi without halting anywhere, except for a meal at a highway dhaba around midnight. We loved the dhaba fare of hot corn-rotis or naans, dal-fry and curd rice. To save time, David and I ate in the taxi while the others sat on a charpoy under the open sky. Seeing a bunch of disabled people on the highway at midnight was intriguing to say the least. Curiosity gave way to admiration and we were proclaimed guests of the village. What's more, we had a free meal! Just as we were about to leave, a group of men came to us and offered us a bundle of currency notes, saying,

"We are devotees of Bhagwan Rajneesh. Here, please accept this as our gift. Use it for your travel."

"No, thank you," I said. "We are all earning people, you are very kind indeed, but we must turn down your offer."

"Then have some paan." I don't know what it was about them but I had an uneasy feeling. They looked like thugs with their beards and moustaches.

"Let's go!" I told the driver. And to everyone, "Throw away your paan!" They must have felt what I did because they obeyed me.

Back in Delhi, Rekha had recovered thanks to Kedar, Khanna and Sood's care. Now it was time to head back home.



On the way we stopped at Baroda as planned. My friend, Hira Patel, had made arrangements in one of the newly constructed (and barely functioning) hostels for disabled people. No sooner had we set foot in Baroda, than I developed a fever on account of my infection. I wanted to rest in the hostel and I told the others to carry on with their itinerary for Ahmedabad and Baroda. But the Matador van which we hired wouldn't move without me, so I had no choice but to call a doctor and take an injection. I was a bit irritated—didn't we leave Rekha behind in Delhi? Then why was it so difficult for them to be a little flexible about *me*? Why couldn't they understand that instead of enjoying the trip I would only suffer?

We reached Ahmedabad and Rajani wanted to part from the group in order to stay with a relative. But this was against the group's policy so I put my foot down. Rajani was cross as hell and my popularity rating was fast plummeting. Kedar nicknamed me "Saudamini" and Rajani seconded it, "You're as quick as lightening, very appropriate!"

"Yes," I thought to myself, "the same lightening that gives light also burns things to ashes!"

No sooner had we settled into our railway compartment bound for Mumbai, than our group attacked me. Only Rekha was quiet; never has she complained about me. Suddenly I felt debilitated, both mentally, as I tried to defend myself, and physically because of the fever. When I met with nothing but a dead wall of resentment, I shut up. My leadership of the tour was certainly not welcome here, so why did I bother so much about the group? This was the reward for my tireless efforts to plan the tour and carry it through. Not one or two, but *all* of them were unhappy with me. The attention I gave to Sukumar seemed a sore point with them, but it was my duty to look after my helper. After all, each one had a person who was taking care of them. Yes, I was strict about rules and sticking to schedules, but how could such a long trip work otherwise? I'd always taken care of the needs of the others before taking care of my own. The only special arrangement for me was a bed without which I couldn't sleep, and anyway, no one had any objections to that. Even today, after so many years, I still can't understand why they had a row with me. Why couldn't we have pleasant memories of the trip instead?

Arguments were something I loathed. But I learnt a valuable lesson in group dynamics on this trip.

But all was not negative. There was the satisfaction of fulfilling Rekha's wish to see the Taj. I remember how she kept saying, "Naseem, had I not met you, I would never have seen it!"

Rekha died on November 23. We both knew the end was near and the last four months before her death were miserable. She had no strength to spend hours at work, yet she came to the office just to spend time with me. When she stopped coming, I went to see her every day after work hours. And every time I was in hospital, she used to speak to me either before she went to work, or during lunch break or sometimes even after office hours. Some days I was too exhausted to visit her, then her eyes would fill up as she told me how eagerly she was waiting for me. Once, on account of extra work, I couldn't make it to see her. The next day she telephoned me. How did she even reach the telephone?

"I thought I would feel better by speaking to you, so I dragged myself up the steps," she was crying.

"I'll come right away," I told her.

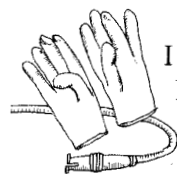
Gaokar Saheb heard me. "Can I go Sir? It's...er...Rekha," I said gingerly. This was the first time that I was asking for permission to see her during work hours. "Should I go on leave till Rekha gets better?"

He said, "Go as and when you feel like it. Wait, I'll come with you."

But, instead of getting better, Rekha died within four days on a full moon night. I sat by her side, holding her hand all afternoon. During the early part of the night she said, "Take me out in the open, I feel claustrophobic." I took her out. I'd often asked her whether she wanted me to call her childhood sweetheart but she always declined the offer. At ten I took her inside and returned home. The doctor had guessed that it could be her last night but no one told me about it. I lay down and fell asleep. The doorbell rang early next morning. Rekha had died quietly at night. I took a rickshaw and went to Mane Bhausaheb's house to give him the news so that my colleagues at work could be informed. Her body was already prepared for cremation. I put my hand

on her forehead but it was not cool as Baba's face had been. I'd hoped that they would wait till our colleagues arrived, but they were asked to go directly to the ghats where she would be cremated.

Rekha, dear girl, how can I ever forget her? It would be like forgetting myself. Rekha who'd always said, "Naseem, get started with your work with the disabled, I'll join you," went ahead without me to meet Babu Kaka.



I was a bit apprehensive before we formally registered Helpers of the Handicapped. I was unsure of my ability to take on this massive responsibility and wanted to evaluate both my own capacity and the nature of the work itself. At that time, I had three young, polio-affected boys with me—Rajiv Vanakudre aged sixteen, Abhijit Gare, twelve and Ashok Shelar, twelve—who, since they were disabled themselves, were sensitive to the issue. I'd begun to realise that ordinary persons, if properly guided, could be very effective. The three boys always responded to my call. From wheeling me to folding my wheelchair to helping me into a rickshaw, they did everything. They were able to visit a beneficiary or go to an office, or accompany teams for an athletic meet. I asked them if they were bored with this sort of work.

"No, on the contrary, we're quite happy doing it," they replied.

Gradually the child-brigade grew in size. Ramesh Ranjane, Ramesh Mane, Praveen Savant and several others joined the group.

It was around that time that Manohar Deshbhratar joined our office on transfer from Nagpur. He offered to write letters for us. His handwriting was neat and he drew well. He was pleasant and easy to work with. He lived alone in a rented room and did all the cooking, washing and cleaning himself. I rather admired him.

We were invited to attend an athletic meet in Delhi. Kedar Patil was a good athlete. Though he was a paraplegic like me, he went abroad every year and won medals. I came to know

that he was going to Delhi and so I suggested to Deshbhratar, "If you came with us, we could take a few of the children too." At first he thought I was joking.

"Why me?" he asked. "Why not our other colleagues like Shirke, Mohite and Chauhan who came with you to Mumbai?"

"Well, for one thing, you live alone, you have no responsibilities, and I guess you can take some leave of absence from the office," I said mischievously.

"Hmmm...well, alright," he said finally, stroking his chin.

Working with him was a real learning experience. He chalked out the entire schedule, the budget and even the packing! Because of him we took some of the children like Abhijit Gare and Ashok Shelar to Delhi and returned with several prizes. On such occasions, Aziz did his bit, giving us a little extra money so that we could also have some fun like sightseeing. The Pirajirao Ghatge Trust reimbursed our travel expenses. I remembered Rekha all through our trip.

Back home in Kolhapur, we happened to be chatting one day in the office. Monteiro, Deshbhratar and some other colleagues were present. In the course of the conversation, I spoke very highly of Deshbhratar—he was polite, had no addictions and was very polite. He was hard working and friendly.

Monterio piped up, "Ma'am, I agree with all that you say, except for what you say about his 'addictions'." Monteiro was a smoker himself. "You see, he's a chain smoker, it's just that he doesn't smoke in front of you. Ask him how many cigarettes he smokes a day!"

I asked Deshbhratar, "Really? When do you do it? I never saw you once during all the ten days that we were together on the trip! Come on, say something!" He smiled sheepishly and shuffled off.

I didn't let go of the matter. In the evening, as we were discussing work, I brought up the subject again. Deshbhratar said, "I used to go far away from you for a smoke so you'd never know."

I said, "Smoking gives you nothing, just unnecessary expenses and bad health. Baba used to smoke too, but he gave it up, but Uncle still smokes and coughs all the time." But Deshbhratar continued to smoke. So I gave him a nice

lighter saying, "Now you can smoke in *front* of me." He lit his last cigarette with the lighter and threw away the pack.

I came to know that he drank as well. One day my colleague, Ms Khadilkar went to his place for some urgent work. She noticed that a drinking session was on and Deshbhratar didn't come to the door to meet her. He avoided me for two days. I, of course, had no right to interfere in his personal affairs, so I didn't raise the subject. But the thought didn't leave me because, since Deshbhratar joined us, I'd been thinking about registering Helpers of the Handicapped.

I wrote an article called *Jhep* (Flight) for a souvenir that came out during the Apang Kreedha Spardha (Sports Meet for the Disabled). I wrote "I need men who can serve as my legs to work with me. I need dedicated men without addictions of any kind. I *know* we can meet our goal." Working alone or just with other women had its limitations. I had pinned my hopes on Deshbhratar but my confidence was now shaken. I had always wondered why he looked so unwell on Mondays. Obviously he'd been drinking through the weekend as Monteiro now told me. I urged Deshbhratar to see a doctor for his alcoholism. Practically speaking, I also didn't think it was very advisable for him to accompany some of the girls to their homes late at night. Besides, how safe would it be even for me? Ma would certainly not have liked it. My dreams of playing a part in the shaping of the future of disabled children with Deshbhratar's help were shattered.

One day Monterio asked me, 'Ma'am, what *did* you tell Deshbhratar? He hardly comes to our parties these days. Even if he does, he doesn't touch a drop of alcohol even if we insist. Amazing self-control for one who drank alone on weekends!"

"It's a miracle!" I thought, delighted beyond words. This, clearly, was an example of how good work can be an influence of change not just in children but also in young adults. I congratulated Deshbhratar. He spoke to me openly about his withdrawal symptoms like weakness, trembling of limbs, palpitations, pain in the chest and so on. We consulted Dr Satvekar and Dr Bhagwat who put Deshbhratar on a course of medicines. Soon his spirits rose and he looked well.

We used our experiences in the Apang Punarvasan Sanstha to make some changes in the rudimentary

constitution that we'd already drawn up for Helpers of the Handicapped. Four people would be permanent members of the Board of Trustees and five others would be elected. I proposed Deshbhratar's name as one of the elected candidates. But since all the other elected members were women, they wanted to keep it an all-woman committee. Premanand Malekar expedited the registration. Rajani Karkare, Vijayadevi Ghatge, Suhasinidevi Ghatge and I were the permanent members. I was a bit upset at the exclusion of Deshbhratar's name from the committee, but he was not one to work for status or power, so he didn't mind.

At around the same time, the 30cc bulb of my Foley's catheter began to get dislocated often. I consulted the urologist, Dr Prakash Gune in Kolhapur who advised me to get an artificial bladder. They make a hole in your tummy and insert a tube which is then attached to a bag outside the body. Ma had seen patients who had undergone this procedure in the hospitals at Miraj and Pune. She noticed that not only were there some other fluids that were being discharged through the tube, but also that urine flowed out through two outlets. Doctors told Ma that medical science had advanced and things had improved, but she said a firm no to the surgery. I was ready, on the other hand, to let my body be used for experimental procedures in search of solutions. I didn't mind donating my organs as well. Like my one eye, which I was happy to donate and so wrote to the eye bank in Mumbai. There was no eye bank in Kolhapur then. They wrote back saying that a living person was not expected to donate an eye, and enclosed a form for eye donation after my death. I filled it up and sent it to them. Please remember this after I'm gone. But, so far, I've not met any one who has received another person's eye and is not blind any more.

Coming back to my catheter problem, I *had* to find a way out. I went to the All India Institute for Medicine and Rehabilitation Center for Handicapped in Haji Ali, Mumbai. I was examined thoroughly and was given a letter which was to be taken to Dr Colabawala, the urologist.

His instructions were clear, "Get admitted to the Jaslok Hospital. I can't say much till I've seen you myself." I stayed

at Jaslok for five days and had a very unpleasant experience. I admit that my catheter problem was not normal, but what was rather amazing was that neither the sisters nor the trainee doctors could fit it in even several attempts later. Finally, I had to put my foot down.

"Let me do it myself," I said.

"Why? Are you here as a patient or a doctor? There's no way you can do this yourself," they argued.

"You can see that the catheter is smeared with blood, and that's not a job well done! Just give me a pair of gloves," I snapped back. It took me about two or three minutes to fit it in. After this, they grew a bit more respectful. Dr Colabawala's verdict was that there was no way out but to put in an artificial bladder. I was completely dejected. Then came a letter from Deshbhratar who was now taking care of matters in Kolhapur. Something snapped in me. I would not break my head over this problem any more, I would carry on the way I was. As long as I was alive, I would just continue doing my work and that was that. I returned to Kolhapur.

Helpers was now registered. Malekar and Deshbhratar managed to complete the formalities in my absence.

One of the first things I addressed at our meetings was how to set right those disability problems in children that could be corrected by surgery in order to make them independent. Most often, the parents of these kids couldn't afford the expenses and the children dragged on with their lives. The meetings were held at my home where I lay on my bed (usually very tired after my full day's work) while the others sat on chairs. No one objected, including Aai Saheb and Suhasinidevi. Perhaps we were the only organisation to hold meetings like this!

I was the Organiser cum Treasurer. It was easier this way to plan projects depending on the availability of funds and then successfully see them through. Normally, someone plans the project and someone else manages the finances and the lack of co-ordination between the two makes the project linger on and on. We decided to raise only as much money as we needed; I hadn't forgotten the earlier experience of what happens when there are extra funds available.

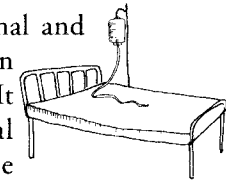
I have always felt that the need for the emotional and mental rehabilitation of disabled people, who often felt inferior, was not something to be ignored. It had to assume the same urgency as physical rehabilitation. We wanted that they should be happy and enjoy living as able people do. For this there should be laughter and play. And so, when the Convenor of Balagram, Mr Babasaheb Jadhav agreed to organise a camp for the children of Helpers in Panhala during the summer holidays, we thought it was a good step in this direction. He was going to look after their stay and food. We made two groups of twenty-five each. The first group consisted of children below twelve years and the other, above twelve. Each group was to stay there for four days. As an exercise in self-reliance, parents were not invited to attend the camp. Besides, the children would feel freer without their parents. We got confirmations from fifty odd children.

But just one day before the camp, Babasaheb informed us that there was an acute water shortage in Panhala and asked us whether we could postpone the camp till the Diwali vacations. The children, many of them from far-flung places had already gathered in Kolhapur. How could we tell them to go back just like that? Wouldn't it be so disappointing for them?

I made a quick decision. I called up the Secretary, Shanta Pathak and President David of the Belgaum Institute whose premises were now ready. I told them about Panhala and the water shortage.

"Could I please bring our children? They're ready for the camp and we can't let them down. We'll get our own provisions and do our own cooking. We need your premises for eight days, free of charge." They agreed most readily, all we had to do was steer the bus towards Belgaum and not towards Panhala. Babasaheb gave us all the provisions we needed.

I engaged a woman who was to function both as my helper and our cook. The children loved the big campus and were all over the place, playing and laughing. They sometimes strayed into the kitchen much to the disgust of the woman. She yelled at them and often humiliated them. I warned her about her behaviour. Her reaction to that was



to take herself to her mattress from where she refused to budge saying that she was ill and needed rest. She didn't help me with my personal needs either, not even my bath. As far as the cooking was concerned, though Shanta and Chhaya Desai helped me in every way, I was ready to handle the kitchen. I was always fond of cooking and could cook most everything. The question was numbers. How was I to manage cooking for about thirty-five people? I entered the kitchen, God's name on my lips. Lo and behold, everyone, young and old, came to help and the food was ready almost by magic. It was tasty too, I'll vouch for that! We made pulao, kanda bhaji and shreekhand. I still remember how the shreekhand bowl was wiped clean by several pairs of little hands! Shanta and David liked the food so much that the next day, they invited their committee members to eat with us. We ran out of pulao and had to hastily make it again. Abhijit Gare, one of our young boys, loves that pulao even today. When the first group of kids were ready to head back to Kolhapur we told the woman, "Now that you're so sick, you must go back to Kolhapur and rest."

Amazingly, she started to wail, "Didi, please, forgive me, I'll do anything, just don't send me back!" So we retained her, but told her not to cook.

During the camp at Belgaum, one day, we took the children to the Mahadeo Garden to see some of the animals there. En route we had to pass through a temple. I stopped at a shady spot to talk to some people and asked the volunteers to continue with the children. Very soon, they were back.

"Why, what happened? I thought you wanted to see the animals," I was surprised.

"Didi, we were stopped by the watchman. He said we couldn't pass through the temple and have to take a longer route," the volunteers said angrily.

Longer route? But these kids could hardly walk! My temper was rising. How dare he? I had to confront him immediately.

I wheeled myself to where the watchman stood twirling his moustache.

"Why...?" Before I could say anything more, the man raised his voice.

"These children are wearing shoes. And you know that vehicles are prohibited, yet these kids are swarming all over the place. Look, do you see that board? Those are the rules," he said, pointing to the board. "Do you want me to lose my job?"

I realised that by "shoes" he meant calipers and by "vehicles" wheelchairs.

Keeping my voice down I said with deadly firmness, "Indeed, if your bosses *do* come to know what you have done, you *will* lose your job, of that I assure you. On the other hand, if you were kind and friendly, you may even have got promoted. These wheelchairs you call "vehicles" are our legs. We are helpless without them."

"I'm sorry," the surly man replied, "you can pray from right here, you can't go in."

By now I was thoroughly disgusted. "Oh no, I don't need to go in to see God, I see Him in these girls and boys. Maybe you could too if you tried. These poor children have come to see the animals. Who's your boss? I'll have a word with him, let the children pass."

But he wouldn't listen.

"Well then," I told the volunteers, "take my wheelchair in first. Children, you follow me!"

The watchman grabbed my wheelchair with both his hands. By now, a crowd had gathered around us and the children were mortified by the scene.

"Didi, let's go back. We don't want to see the animals."

Shanta and David seemed to agree with the children, especially since we were in their city.

I was angry and exhausted by what happened. Should we be humiliated like this just because we are disabled? Don't people understand that the disabled, in particular, have a dire need to see a film or go to a garden once in a while in order to forget their bleak existence and unending hardships? Would the watchman have behaved like this if *his* son was disabled? A hundred ants nibbled my brains and my pulse raced.

"Take your filthy hands off my wheelchair!" I was furious with the watchman. "Or else you will be held responsible for the consequences!"



And to the crowd gathered I said, "See how this watchman here is bullying these kids and not letting them see the animals? Are you going to just stand there and watch?"

Before I finished my sentence the crowd surged forward and pulled the watchman to one side.

The children went in, but they were silent and grim. As we passed through the temple, we saw a man on a cycle going in. We returned home without exchanging a word between us.

The night passed quietly. The next morning, the first group was ready to depart. I asked them, "What is your reaction to yesterday's incident?" The purpose of the camp was to boost their sagging morale, get them to fight for their due place in society and to make them fearless and bold about their disability. I was afraid that what happened the previous day could be a setback. Could it leave a permanent impression on their sensitive minds and dampen their spirits? I was restless through the night.

The answer was a bit unexpected, "Didi, we learnt yesterday that we should get what we need by being soft and polite at first but also have the courage to put up a fight if it doesn't work. We are not yet as fearless as you, but we'll try." That was just what I wanted to hear. My tears were tears of happiness. I wiped my eyes quietly and began our preparations for the second group.

Sometimes we took the children to the sea. Each of our trips was something to cherish. Once, a whole group of us, young and old, went to Chiplun and Guhagar on the Maharashtra coast. It was raining cats and dogs by the time we reached Chiplun. So we proceeded to Dervan where the Walawalkar Trust had an exhibition called Shiva Srishti, episodes in the life of Maharaja Shivaji, and then to see the Enron project. For the children the ocean always held a special magic. The Border Security Force gave us a boat and we went boating, the children screaming with delight as the boat bobbed up and down on the waves. We decided to go a step further that evening. For about an hour we abandoned our wheelchairs and crutches to gambol in the water. It was marvellous, I have no words to describe it! A small lame child was all smiles as he said, "Didi, I'm having so much fun playing in the water! My mother never lets me play in the

rain or in the mud." Saying which, he immediately proceeded to make a sand castle digging his hands up to his elbows in the wet, slushy sand.

The holiday camp in Belgaum had its uses. For one, we felt a new confidence about our culinary skills. We started taking orders for snacks and meals, cooking at the Helpers office (which, at that time, was my rented flat). We began by supplying clean, fresh and tasty food for my office functions. We got more orders, and since we were earning revenue for rehabilitation work, both office bearers and volunteers began to help. In fact, we became such experts that our food stall, which we put up during the Sahitya Sammelan in Kolhapur, became legendary! Helpers used to put up food stalls at various public functions. Someone had gifted us a second hand fridge so now that we had a constant supply of milk, we made tea and coffee right through the night. Kanda bhaji (onion fritters) and bhelpuri (a puffed rice savoury) were the main attractions with people queuing for them even at midnight. We sold food worth Rs11, 000 in just five days! Our moment of ultimate triumph came in the form of the famous bhelpuri maker of Kolhapur, who having heard praises of our "lajawab bhel" (bhel that defied all description), visited our stall one night. I used to rest on a bed near the stall; a friend had given us a room nearby where we rested in turns because our stall was open twenty-four hours.

Fund raising was a real challenge and we had to innovate all the time. The waiting list of disabled people wanting help was getting longer and we didn't know how to meet their needs. So when the Ganapati festival came, we offered coconuts at every pooja pandal and got some money in our donation boxes. But it was not smooth going, because I came under the disapproving cynosure of the Secretary and President of Helpers. One day, they pinned me down at home saying, "Does it look good that the children dance and you join them at these different pooja venues? Most improper and inappropriate we say!"

I retorted, "What's so improper? The children are just singing and dancing, they're not using any unfair means. They've been trying to raise money for us without thinking about themselves, not eating and drinking for hours at a

stretch. I joined them to boost their morale. My folks have no objection, so what's the problem, I fail to understand. Besides, I had to make sure that the children ate on time."

Our course of action inevitably depended on the need of the hour. The bitter experiences of the past paved the way for our learning and helped us take every new step with utmost caution. On World Disabled Day, we organised medical examinations, surgeries, artificial devices, athletic meets and cultural programmes. Several orthopedic specialists of Kolhapur gave us their unstinting medical help. Generally, we didn't take up another project until we finished the work of each camp, one hundred per cent. Accordingly, first we had surgeries. Instead of sending thirty to forty people along with assistants to Mumbai for prostheses, we decided to import NASEOH technicians from Mumbai to Kolhapur. We would reimburse their travel expenses and made arrangements for their stay. That year, NASEOH had supplied us with prostheses worth one and a half lakhs and similarly, the next year.

Rehabilitating children was Helpers' first priority. Dr Satvekar agreed to perform operations free of charge. But operations required medicines, saline fluids and blood for which we had no funds. I asked the Jaslok Hospital in Mumbai for help, but I had no luck there. Sometimes I got so frustrated and pushed against a wall, that I would spend the whole night crying. I just wanted to die. The next morning my eyes looked red and swollen. To camouflage the horrible, weeping night and my fat eyes, I wore my best sari so that I'd appear cheerful. Ma would always urge me to wear some ornaments and I always refused. But on such days I wore some so that no one would notice my swollen eyes. Instead, I was complimented for my sari and jewels. A friend of mine, on my advice, resorted to this trick once in a while and met with great success.

Try as I did, I couldn't come to terms with my disability. I was able to put it aside as long as I was busy at the office, but once I came home and lay down on my bed, I was besieged with the most abject depression. My stomach ached and so did my head. My insomnia was another problem I had to deal with. After several sleepless nights, I increased my dosage of sleeping pills from one or two to three or four. But I had to pay a price for it the next day. I felt weak, my

hands shook and my throat went dry. One day, I had to take care of some organisational work after my office hours. But the effect of the pills made me so fuzzy that I just couldn't do it. I came home furious with myself and threw all my sleeping pills out of the window. It was an addiction, I told myself, just for the sake of a few hours of sleep. It was certainly not a permanent solution, on the other hand, it had adverse effects. From that day onwards, whenever I couldn't sleep, I lay on my stomach and worked on my correspondence. The advantages were twofold. One, I had no hangover from the sleeping pills the next day and two, my correspondence was up to date. The next day I gave my letters to the office peon to post. This way, I could pay more attention to the joys and sorrows of the disabled people who wrote to me.

But then, either because of lack of sleep or for some other reason, I got jaundice and had to be admitted to hospital. I was put on a diet of boiled vegetables and lentils. No oil, no chillies. I was given molasses and cane juice and sweets which I didn't like one bit.

I was in hospital for twenty-four days during which time I couldn't get a wink of sleep. It was then that I realised that one could *actually* live without sleep. Deshbhatar, Rajani, my colleagues and friends worried for me and came to see me regularly. I had severe headache and vomiting but when visitors came, I smiled and spoke a lot. Just as soon as they left, I started moaning again. Ma was cross, "Where was the need to talk so much? No one would have believed that you were in such pain!" But the last thing I wanted from my friends was pity, so I'd put on a brave veneer. Both my hands had turned blackish because of the saline drip so I requested the doctor to put the needle into my leg so that my hands would be free to do some work. I resumed my letter writing and crochet work. My vision was not affected so I could read.

Everyday I asked the doctor to give me sleeping pills, but my condition was so fragile that I could easily slip into a coma. No sleeping pills, the doctor was firm. My blood was checked daily. One hot day my throat was parched and I was continuously thirsty. I'd been eating puddings, fruit salads

and cold kheer. My throat was still dry, so I asked for grapes. I must have eaten perhaps a kilo of them or even more! Soon, my dear old friend, Mr Sleep, who was annoyed with me all these days, began to sit heavy on my eyelids and I began to nod off. My blood report arrived just then.

The doctor's voice was panic stricken, "Her sugar level has gone way up, don't let her sleep, it could be dangerous, she could slip into a coma. Someone play cards with her, switch on the radio, something! Just don't let her sleep!"

Aziz's friends told me jokes, everyone was sitting up so that I wouldn't sleep. It was too much for me and I pushed away the cards. The radio was on but I fell asleep, I don't know for how long. I dreamt of fairies with wings in white dresses. They were smiling and talking ever so sweetly.

Then I heard voices, "She hasn't slept for twenty-four days, let her sleep for a while."

"No, No! Enough! She's slept for five hours. The doctor has warned us not to let her sleep."

I was waking up in a haze. I still can't remember who woke me up or who was in the room at that time. Everything was such a blur that for a moment I thought I'd gone blind. Whose was the face nearest to mine? Where was I? Why was it that I could remember nothing? Oh God, help! I've gone insane! All hell broke loose and I started crying.

I was told later that I behaved like a mad woman, "You had the strangest expressions on your face and your mannerisms were abnormal to say the least!"

At midnight, Ma told Aapajaan to feed me some coffee and biscuits which perked me up a little. My crying began again, this time louder than before because I thought, oh, God, I may not be able to even recognise my own hunger till *someone else* realises that I haven't eaten and feeds me! I am a vegetable...my brain is dead. Ma must have been weeping silently. She heard me sobbing and said to herself, "She's not only disabled, but insane! How will I look after her?" She looked shattered.

"Shhh....calm down, Naseem. It's only because you've gone without sleep for so many days. There's nothing wrong with you. The doctor's coming," my family was trying to console me.



He gave me some medication and I slept peacefully. I had developed short-term diabetes and was put on insulin for several days.

Aziz extended his leave because my illness had now taken a different turn. I was convinced that I was going to die and gave away several of my fancy imported saris. Naturally, my friends were embarrassed about the whole thing, but I said, "Take them please, don't disappoint me."

I was in hospital for about two and a half months and as the days passed I began to feel stronger. Rajani came to visit me several times and brought along PD Deshpande, her brother's friend, with whom we had long discussions about our work at Helpers.

My mental and emotional condition was very fragile those days. I begged for euthanasia. I wrote to Vijay Merchant, who agreed that euthanasia was a good thing sometimes, but prohibited by law. Speak to your doctor about it, he urged. I was trying to turn the idea over and over again in my head. So Ganga Shende was not the best thing to happen to me at that time.

Ganga's father used to drop in every day around dinnertime with his daughter. She was around twelve, monstrous looking with a big head and saliva constantly drooled from her mouth. We had arranged a wheelchair for her through NASEOH on which she now sat with her father wheeling her around. He brought her to show me out of gratitude perhaps. She couldn't move her hands or feet and she was retarded too. Notwithstanding her pathetic condition, her father adorned her with silver earrings, necklaces and even anklets. It was altogether depressing, especially as she sat there for more than an hour just drooling away. At a time when I was actually negotiating euthanasia for myself, the sight of a disabled, drooling and bejeweled Ganga was something I couldn't take anymore. It was difficult for me to eat my dinner after they left. Ma understood and she said, "Let's tell him not to come at dinnertime." But I didn't let her. Fortunately, the doctor, fearing another bout of insane behaviour from me, banned all visitors, barring a selected few people, from coming to my room. Many years later I heard that the man had left his wife and daughter and was living with another woman. So much for the love he had for his daughter.



Once when Rajani and PD came over, PD asked me, "What do you think of a fund raising programme with Suresh Bhat?" Bhat was a respected poet.

"Well...er...okay," I said, "we really need funds for surgery cases, don't we?" I sat up, leaning against a backrest and began to make plans right away. Ma objected to this saying that I was hardly well enough to get involved with work but I knew that work was my best remedy. One day with Dr Satvekar's permission, I went to meet Suresh Bhat. This annoyed Ma no end. She said, "What am I to tell your visitors? That they should be happy seeing *me* here instead of you?" Ma had a point but Suresh Bhat was going out of town and we had to sort out matters like his fees and other expenses for the event. As Organiser cum Treasurer I *had* to look into things. When we returned an hour and half later, Ma was so annoyed that it was difficult to placate her. I told her all about my meeting with Suresh Bhat who was disabled himself. "Today I'll be able to sleep at last! I was sick of being in bed for two months," I told her. Ma cooled down finally.

I was put on a strict diet for four months. I decided to go and spend some time with Rehana after my discharge from the hospital. We planned an evening of Marathi ghazals by Suresh Bhat in the Keshavrao Bhosle Natyagriha after my return.

Meanwhile, my blood sugar returned to normal. But I still had trouble with my catheter. From a 5 cc bulb, I'd gone to a 35 cc and that was its limit. But that kept slipping out too.

"Let's try urethraplasty, but there's no guarantee," Dr Satvekar said.

"We'll never know if we don't try," I said. "Let's do it while I'm still in the hospital, or I'll have to take leave from work yet again just for this."

Dr Satvekar agreed and so did my folks but only because I insisted. Actually, I had little choice. I was the same as I was in 1967, in other words, back to square one as far as my catheter was concerned. How could I work in the office for eight hours and then manage the work of Helpers in this condition? I *had* to have surgery though I was warned that I could get bed sores.

I entered the operation theatre for the third time. First, my spinal cord was operated upon and then my appendix,

which was inflamed, was removed. This time round, I said no to chloroform, so I was given a local anaesthesia. I seemed to be alright on the first day. But the next day, my blood sugar level shot up and I bled profusely from my urethra. My sheets were drenched with so much blood that they had to be changed constantly. I was about to pass out. I heard the word "transfusion" but fortunately, I pulled through without it. The bleeding stopped but the operation had failed. I had to visit the operation theatre once more. I hoped that that was the end and I didn't have to go again for the fifth time.

As I mentioned earlier, my physical condition was in the same bad shape as it had been before I went to Bangalore the first time. Now I was truly afraid—would I have to leave my job *as well as* Helpers? It so happened that at that time the office was allotting flats to its employees. Deshbhratar offered to spare one of the rooms in his flat as an office for Helpers. Our Supervisor JG Patil (fondly known as Patil Kaka to all of us) had begun to take a keen interest in our disability work, often getting us donations. We asked him what he thought of the idea of us using one of the rooms in Deshbhratar's flat as the Helpers office. Knowing my condition, he suggested that I should apply for a separate flat in my name, so that I could rest in one of the rooms during lunch break and use the rest of the space as our office. Moreover, if Deshbhratar got married we would be infringing on his privacy. Patil Kaka was right. Gaokar Saheb drafted my application in which he wrote that I was a disabled person who had the added responsibility of running an organisation for disabled people. It was getting increasingly inconvenient for me to stay with my brother and his family (though Ma, Irshad or Aziz never complained) because our home was now converted into an office and they had absolutely no privacy. Helpers badly needed an independent office.

I got a spacious flat with three bedrooms on the ground floor and Deshbhratar got one on the floor above. We set up our office. We bought a table; two chairs and a bed came from home. We employed Rajiv Vankudre on a part time basis so that he didn't have to leave college. Our work progressed smoothly—listings, surgeries, supplying artificial devices and so on. But ironically, here I was, beset by massive physical problems.

We managed to sell a fair number of tickets for Elgar, Suresh Bhat's programme, slated for 5 March 1985. Just one day before the event I was told that he was going to sing his ghazals himself and Rajani Karkare would sing just one unlike what we had planned earlier. All along I was under the impression that Rajani, with her beautiful voice, would sing most of them, because though Suresh's poems were very soulful, his voice was not. I told PD that most of the people who'd bought tickets were keen to hear Rajani and not Suresh, so I insisted that I be taken to meet him. I tried explaining gently but he didn't agree. So I suggested that Rajani could sing half the number of ghazals to which he also said no. No doubt, Suresh's ghazals were poignant and soul stirring, but people wanted to hear Rajani sing them. So I was not surprised to sense that, on the evening of the event, the audience was quiet but restless and soon they started to leave one by one. In fact, there were only a handful of people after the intermission. Suresh Bhat announced over the mike, "Will the audience please come forward, only real connoisseurs stay till the end." Rajani got her chance after the intermission. After that the hall was practically empty. Only some of the office bearers, volunteers and wellwishers (in order not to hurt us) stayed on. If only Bhat had listened to me, the Karaveerwasis (people of Kolhapur) would have enjoyed his ghazals.

But Elgar had one advantage—it gave us Susheel Nashikkar, an engineer in the Public Works Department and friend of PD's. Even today his selfless dedication sustains Helpers.

We had many charity programmes after that, but they were based on a decision I made as I returned from Elgar. We would check things thoroughly before we organised one. The 10,000 rupees we collected were put into the kitty. PD proved to be a pillar of strength as did Shreekant Kekde, an inspector in the Central Excise and Customs, who sometimes ate lunch with us. He was an expert with English correspondence and making agendas for our various projects for which he spared some time on Sundays. Since I was an office bearer I had to put my signature on various documents which were drafted by Kekde or PD and typed by Deshbhratar. While they did

this I made tea, hot onion fritters, halwa made in ghee, pohe, carrot halwa, coconut barfi and other goodies. Sometimes we played caroms or chess in the other room.

When we met on Sundays, the first thing we did was to classify disabled people according to their needs and took decisions based on the most economically viable solutions. Whenever there was a medical camp for disabled people in Kolhapur or nearby places, we took *our* patients there as well. First we mailed them a postcard and got them all assembled in one place. Then with packed lunches, we took them to the camp. All expenses were ours. Our young volunteers, Abhijit, Rajiv and Ramesh accompanied Deshbhratar and myself. Once we finished with whatever was to be done for our patients, we attended to the other disabled people who were visiting the camps. We filled in their forms, had them examined and so on. They came to us because they thought we were one of the organisers.

In May 1985, there was a camp in Belgaum, a training programme for young children. We sent five of our students. Then, during another camp in Ichalkaranji for the hearing and vision impaired, where free hearing aids were being distributed, we again sent some of our kids. Dr Dilip Deshmukh and Mr Sudhakar Chandekar noticed that our children used to have fun chatting and singing but they were also disciplined. They were pleased with this and wanted us to send a group again for another camp which they were organising in November 1986. This was a training camp for young adults, where their stay, food, and events would be taken care of.

On the last day of the camp the children were desperate to play cricket. In fact, for a long time, our children had been urging me to form a team and ask NASEOH to hold a cricket match in Mumbai. I dared not do something like this without consulting specialists. But Dr Deshmukh and Chandekar Saheb gave the kids the go ahead and the match was on! It was an amazing performance. There was Maruti, bowling, batting and taking catches with one hand, a boy with one leg, on crutches, was batting away. Winning or losing was the last priority, what was important was that they seemed to have totally forgotten their disability. Neither those on the



pitch nor the spectators seemed to mind the sun beating down on them. It was pure joy for the kids.

After the match, we got an appointment with Vijay Merchant. Deshbhratar, Pramod Shah (a new entrant whose one leg was very short) and I went to see him. We requested him to float the idea of a cricket meet for disabled people at the next NASEOH meeting. The members of NASEOH didn't warm up to the idea, but Vijay Merchant, being a cricketer himself, was ready to hold it personally. We fixed the date and then made special rules keeping disability factors in mind—the boundary line would be a little closer, more players would field, what degree of disability would be allowed in the team and so on. The match would be held at the Brabourne Stadium in Mumbai and the responsibility was given to Arundhati Ghosh, the well-known woman cricketer.

The match took place as scheduled. On one occasion, Imran Khan, the famous cricketer from Pakistan, happened to be present. We wanted to be photographed with him, but we felt a little shy about asking him. But he agreed easily much to our delight. Our photographer was so excited and confused by Imran's presence that the poor fellow took the picture without removing the lens cap of his camera! Fortunately for him, the team didn't beat him up! But we made up for it by getting frequently photographed with the likes of Sunil Gavaskar and Ajit Wadekar on many occasions.

The prize distribution was to be held that evening and Vijay Merchant was going to give them away. But he had a heart attack in the afternoon and was rushed to the hospital. So I was asked to do the honours. I obliged since it was a last minute affair, but no one was really excited that evening as we went through the motions. We remembered him all the time. We were delighted when he recovered completely soon thereafter.

Soon cricket matches were held regularly at district, state and national levels. Our next dream was to take such cricket to the international level. But gradually, this took an altogether different and unpleasant turn. Every year, four or five players from Helpers formed part of the Maharashtra team. Very often, the captain was also from Helpers. Soon, priorities began to change. Winning a match started becoming

more important than providing a platform for disabled people to play. Selections were made with this in mind to such an extent that spectators commented that they couldn't detect any signs of disability in the team. This was easy enough to accomplish with fake medical certificates. I was getting increasingly busy, juggling both job and the growing and demanding work of Helpers so that I had little time for cricket, or any kind of sports for that matter.

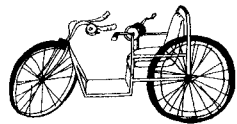
I had only one simple advice to give the team, "Go on, use your initiative and attend meetings to raise your voice against malpractices." But, it was clear from the token fifteen-day practice which they did at our insistence (with Helpers bearing their expenses), that they had no intention of raising their voices against any malpractice. That was the end of any responsibility they had towards the organisation. Sandeep Ankle was the only one in the cricket team who considered the concept and philosophy of the work done by Helpers more important than winning at sports.

I decided that when I retired from my government job, I would organise a team of genuinely disabled children to play cricket and re-prioritise our aims in doing so.

A few years ago under the aegis of the Maharashtra Cricket Association, Helpers organised a state-level cricket meet in Kolhapur. We made arrangements for stay and food at the Chandvani Hall. The matches, which were played at the Khasbagh Stadium, were reported widely by the press. The people of Kolhapur rose to the occasion, leaving no stone unturned. They helped us with breakfast, lunch, prizes, arrangements on the grounds, transport, commentaries—everything. Balasaheb Patankar, President of the Kolhapur District Cricket Association inaugurated the event and Mohan Bhuiambar, the Secretary, gave us a big hand.

Before the state-level meet, we held one-day district level matches in Kolhapur at the Shahupuri Gymkhana. When the Kolhapur team won, there was wild jubilation with children dancing and singing to the rhythm of dhols and tashas, smearing gulal on people's faces. They walked in a procession all the way to our home. Watching disabled people playing cricket was a novel experience and attracted a large crowd.

Mohammad has no hands, so he wielded the bat from under his armpit and hit a four; yet others were on crutches. But why should I go on like this, I can hardly describe it well enough. If you want to see them play, you can come on a Sunday and see for yourselves. We call Mohammad *our* Mohammed because a government-run home for disabled children, fearing that they would have to engage a helper just for him, refused admission since he has no hands! The same applies with regard to inclusion in mainstream schools even today with many of our children being turned away at the door.



Medical rehabilitation was a key focus area for us. We made small groups and had the children examined. Then, according to the advice of specialists, they underwent corrective surgery or were given artificial devices or prostheses. With a bettering of their lives they could then be persuaded to get an education. The only condition was that we would arrange for the surgery but they had to participate in both sports and field trips when they got better. Parents had to stay away. Further, they were given practical lessons in self-reliance and soon they began to experience the joys of being independent.

In May 1986, when the school exams were over, Dr Satvekar conducted medical examinations at the Mary Wanless Hospital. Several children needed surgery.

As I mentioned earlier, Dr Satvekar operated free of charge, but funds were needed for hospital fees, rooms, nursing, medicines, blood and so on. Some families were so poor that they couldn't even afford to give milk to their post-surgical children. We arranged for milk and eggs; sometimes they came from my home. We sent raw materials for food to out-station patients. The list was long and the needs many. So we took patients on a first come first serve basis. When the groups and dates for surgery were finalised, we informed the parents. Then came the arduous task of fund raising for each individual case.

Ujwala was a very pretty, sweet-natured girl whose leg was badly affected by polio. The doctors were sure that she

would be able to walk after her surgery. We put her in the third group which was to have surgeries later, but her father requested that she be operated on sooner because there was some pending work on their farm on account of which they wouldn't be able to come later. We saw their point and Ujwala had her surgery. Those days, Deshbhratar and I used to wait outside the operation theatre and left only after the patient came out of anaesthesia. Ujwala's surgery was a success. As she came out of anaesthesia she writhed in pain and just to distract her I asked, "Do you like to play? Will you come with me to Mumbai for athletics?"

"Oh, Yes!" her eyes gleamed. I told her stories of our sports gatherings and our trips to the sea.

I had a question for God as I left the hospital, "Why do sweet little children like Ujwala have to go through such agony?" I was still talking to God about this as I wheeled myself into the blazing sunshine.

The next day, after office hours, we went to see our little ones who had surgeries. "We will have a picnic and singing sessions in the hospital garden when you get discharged," I told them as smiles lit up their pain-wracked bodies. The moon was full and the night was cool as Deshbhratar escorted me home. I ate my dinner and fell fast asleep. The phone rang early morning. It was Ujwala's father, sounding scared.

"Ujwala has had a fit, she doesn't seem normal," he said. Each parent had been given my phone number at which they could call me any time. Aziz, sweet, loving chap that he always was, seeing that I had to call doctors sometimes on an emergency basis, had ordered a phone in my name. I lost no time and called the peon who was on night duty at the office. He passed on a message to Deshbhratar to reach my home immediately. I got ready and within half an hour, reached the hospital. We were just in time to see her convulse with a couple of spasms and then her head dropped. Ujwala was dead.

This was the same little girl who was so excited at the thought of being able to stand on her legs that she forgot her pain, who dreamt of going to Mumbai; this was the same girl who now lay lifelessly on the bed. I didn't have the courage to touch her. As I stood there staring at that little body, I could hear only the warning words of the President and Secretary of



Helpers ringing in my ears, "Naseema, surgeries are risky, let's avoid them. Let's try everything else. What will you do if a surgery has a fatal consequence?"

But I'd argued, "Yes, that cannot be overruled. But just because of the odd chance that one of the cases could end up being fatal, can we ignore the fact that corrective surgery is their only last chance for a better life? How can we let little children drag themselves around with disability throughout their lives?" I was so adamant that the committee had to agree. But now what was to happen? Will the committee ban surgeries? Will there be hundreds and thousands glued to their wheelchair like me? I was lucky enough to be able to afford a good imported wheelchair, but what about these kids from poor backgrounds? I was so overwhelmed by these thoughts that I didn't know when I started crying inconsolably in front of everyone, right there in the emergency ward. Suddenly, there was a reassuring pat on my shoulder. It was Ujwala's father. "Didi, it's alright, don't be so upset. Ujwala is gone but all the children at Helpers are *my* children now. They'll take Ujwala's place. I'll be associated with your organisation, I'll even attend your medical camps," he was most consoling. Ujwala's mother wept quietly. I called the ambulance and Deshbhratar and I escorted the body to her village.

The possibility that the committee would place a ban on surgeries plagued me as I returned home. Well, even if it did turn out that way, I would still go ahead with surgeries if the *parents* wanted them and if Deshbhratar was ready to help. I felt a little better as soon as I took this decision.

Even before my tears dried, Mr Pardeshi arrived from Delhi with his family. He was an office bearer of the Institute for the Welfare of the Handicapped, Delhi. He had only one hand but he was an accomplished artist. Not that I know much about painting, but his had something lively about them, just like his mind. I invited him for lunch at my flat. The first thing he asked me was, "Didi, why do you look so sad?"

"Do you have some time? Will you come with us to the hospital?" I asked.

"Yes, let's go," he said.

Deshbhratar and I took him to the Mary Wanless hospital. I introduced him to the children who had had surgeries. I

told him all about Ujwala's death and some of my future plans. He was most impressed to see that a small private organisation was taking such a major responsibility in conducting these surgeries. Soon he returned to Delhi.

That was May 1986. In July of the same year I received a letter. I was to be honoured by Mr Pardeshi's Institution in Delhi for social work. Mr HL Kapur, the Lt Governor of Delhi, would give me the award on 15 August, Independence Day. I was to get a citation and a cash award of one thousand rupees and of course, my travel expenses to Delhi. That was my first award.

About fifteen days after Ujwala's death, her father phoned me. I was thrown back by what he said.

"Ujwala's death was caused by the doctor's negligence. I'm going to file a case. You must not misunderstand, please," the voice was cold and firm. He said he was talking from the office of some political party.

I froze. It didn't sound like the man I knew. "Well, why don't you meet me, we'll talk about it" I said calmly, hiding my panic.

Doctor's negligence! Would that mean Dr Satvekar would get into trouble? Would he continue to operate on the children?

By the time I reached the hospital, my heart was beating so fast that I couldn't breathe. Satvekar heard me out fully but retained his composure without flinching even a tiny bit.

"Don't worry, Naseema, I will continue, the surgeries will go on. Send Ujwala's father to me. I'll show him the records. Even if he files a case he can't hurt me," said this noble doctor who had helped hundreds of children stand on their legs.

It turned out that Ujwala's father never showed up nor did he file a case. Many years later, in 1998, I went to his village to give a lecture at the invitation of the Sahakari Bank which had donated money to Helpers. I alluded to Ujwala's case during the course of my talk. After the lecture, her father met me, "Didi, I dropped the case only because of my respect for *you*. Else, I would have taught that doctor a lesson."

I didn't know what to say. How would he ever understand Dr Satvekar's role in giving poor disabled children a chance to lead normal lives?

Fortunately, the committee's decision after the Ujwala episode was not a complete ban on surgeries. They decided



that parents should give a no-objection certificate if they wanted their children to be operated upon. This certificate exonerated us from responsibility for any fatality that may ensue during a surgery or the post operation period. And luckily for us, Ujjwala's was the only such case. Helpers spent Rs 12,66,000 on surgeries for 274 children.

Those days I was preoccupied with several things. Ujjwala's death was one and the other was Ma's protestations about my spending too much time out of the house. They expected me to return home immediately after my official working hours without "wasting time" even to have a cup of tea with my colleagues. I, on the other hand, expected them to be concerned and say, "Are you tired? Here, have some tea or sherbet." Instead I had to face an inquisition like an accused in court, "Where were you? Why are you so late?"

My casual and cursory reply each time angered them even more. I said nothing more than, "I was busy." Normally I blurted out all the day's events in every minute detail. But this kind of interrogation was just not on! I used to change my clothes, drink some water and, since I was tired anyway, lie quietly on my tummy, sometimes even eating dinner in that position. I wrote in that posture too. Aziz was in the habit of arranging for the whole family to have dinner in my room so that we could all eat together. Very often I couldn't sleep through the night, so I read, wrote or crocheted.

Rehana and Bhaisaab came to visit once. We were chatting about Helpers and my work with disability. I told them that everything was fine except for Ma's constant disapproval. I don't know what transpired between them and Ma, but suddenly, she slackened her strict rules. In fact, she even apologised to me. Now I work regardless of time and it is Ma who looks after me—clothes, food and packing my suitcase for my various trips. When she's away, my sister-in-law, Irshad, takes her place with the same sincerity. Since they are forever stretching themselves to nurse me, I feel wretched when one of *them* is unwell and I can't help in any way. What's more, they refuse to let me help. And worse, they have to attend to *me* even if they are sick themselves. That's when I curse my disability the most. Helpers keeps me occupied all the time,

even when I'm needed at home sometimes which is when I become a sort of split-personality with my mind at home and body at work.

I had to go to Delhi to receive my award, but I fell badly sick. Deshbhratar goaded me to undertake the trip and I agreed reluctantly. Vishranti, his sister accompanied us. By the time we reached Delhi, I had vomitted so much that I couldn't even have a sip of water. I had a raging fever too. It was my catheter infection acting up again. Every time it slipped out I had to insert it again and that gave me a lot of pain.

We stayed with Premila Kapoor, a friend who worked at the Railway Board. She was polio-affected in both the legs, using calipers when she went out and a wheelchair at home. I was getting more sick everyday with no strength even to sit. Premila and another friend, Uppi (Upendra) were very worried. They massaged my head and hands gently and a doctor came to give me injections.

On the day of the awards, I managed to go through the motions in a daze. Pardeshi, Gautam Khanna, Sandeep Sood and several others said that it was particularly significant that the award went to someone who was disabled herself and worked for the disabled. I was too weak to respond in any significant way.

I asked Premila to call Rehana in Mumbai and inform them about our departure from Delhi. They said, "Send her by air. We'll receive her at the airport. Let Deshbhratar and Vishranti follow by train." But we already had our return train reservations in an air-conditioned coach.

I asked Deshbhratar, "Are you frightened to travel with me in this condition?"

"Why should I be? The answer is no," he replied.

"Well then, let's pack up and get ready for the train," I said. And to Premila I said, "Tell the doctor to give me something so that I stay asleep till we reach Mumbai."

Rehana wanted me to get admitted in a hospital in Mumbai but I always felt most comfortable at the Mary Wanless in Kolhapur and wanted to get there as quickly as possible. Then I would be in their hands.

I thought about the award. Should I be feeling excited about it? Wasn't it a bit too early considering that we had just



begun work? Did I deserve it? The award served only to increase my responsibilities. I resolved that I must be worthy of it by making sure that every single disabled person in Kolhapur gets some sort of device to improve the quality of his or her life. I knew from personal experience how dreadful life was for me when I didn't have a wheelchair for a whole year.

I bought Ma a pair of earrings with my award money. It was she who taught everyone in my family, including me, to come to terms with my disability. She was always partial to my needs even at the cost of neglecting other domestic ones. In my nine years of working life, I'd never bought her a single thing. Normally, she never took anything from anyone, but she accepted the earrings. It was Ma who deserved the award, not me.

As soon as we returned from Delhi Deshbhratar announced his engagement to Neeta, a girl from Nagpur. I was happy for him and curious too. What would she be like? Would she get along with me? Would she mind her husband's work with Helpers? Were we going to have another helping hand?

As if he'd been reading my thoughts, Deshbhratar said one morning, "You see, Neeta has done a course in Social Work, she is bound to take an interest in what we do."

I couldn't wait to see her but couldn't go to their wedding either because of my being ill. All I could do was send them my good wishes.

Once they were married, I called them over for dinner so that Neeta could meet everyone. She was younger than me so Deshbhratar suggested that I could call her "Neeta" and not "Neeta vahini," a respectful term in Marathi for sister-in-law.

In the beginning, Neeta was a bit brusque with her words. Someone heard her say once, "Oh, I've seen and worked in many big organisations. Comparatively, Helpers is quite small." True, I thought, but inappropriate to declare it like this considering she was a new bride and was just getting acquainted with us. There was another episode where I accidentally dropped my paper and pen on the floor. As usual I asked Deshbhratar, "Would you pick it up for me?"

Neeta burst out, "Didi! Please don't ask him to do such things. Ask *me* instead!" Deshbhratar was silent and I controlled my tears.

But when I worked late Deshbhratar stayed back too. I used to urge him to go home but he always refused. The last thing I wanted was that either Helpers or I should be the cause of any marital rift between the two. So I took the files home. Neeta was newly married and probably had expectations of her husband.

Soon Deshbhratar began to join us for lunch at my flat and I invited Neeta too. I asked her for help when there was extra work or when we had orders for supplying food. I also got orders for making bed sheets and pillow covers and she helped me with that too. Sometimes Neeta asked me to stay on for dinner.

Neeta was good with everything she did. I loved her delicious meals and admired her excellent stitching and good typing. Soon the tensions evaporated and Neeta became my right hand. She came with me to Delhi, Mumbai, sports meets, wherever. She gave me a hand with income tax matters and meetings with the Commissioner of Charitable Trusts. She went with me to Udyog Bhavan and the Collector's office. But most of all, she never neglected her home and juggled both home and work most admirably. Since she spent so much time doing work with us, we began giving her a small honorarium.

Soon she began to handle the work of Helpers on her own and quite successfully at that. She was a past master at using whatever it took to get the work done—politeness, fighting or sometimes, even crying. Neeta was really becoming one of us.

Sometimes Neeta took me by surprise. Here's an example. Once, it was a particularly long day at my workplace and I had come to my flat to wind up some pending work of Helpers. I was exhausted and nearabout dinnertime, just as I was about to lock the door and leave, a disabled person, obviously not from Kolhapur, came to register himself with us. What an odd time to come, I thought, a bit irritated. In a snap, my tiredness got the better of me, so my annoyance must have conveyed itself when I told him, "Not now, you may come tomorrow for your registration."

But Neeta, who obviously read my mind, said, "Didi, my husband will escort you home. I'll attend to this gentleman. He's come from a long distance and I wouldn't



like to send him back.” I was touched; Neeta knew that I would have spent a sleepless night if that person was not registered with us that very day.

Deshbhratar and Neeta shared their meals with our patients very often. Eventually, they shifted to a flat just opposite mine so that it was more convenient for us to work together. Neeta helped me and looked after me just like my mother, sisters or relatives would.

After Deshbhratar, it was Rajani’s and PD’s turn to get married. Though they shifted to Nanded they always attended some of our important events.

One of Helper’s main missions was to procure artificial devices for disabled people. So we took some of our applicants to an out-station camp to get calipers and tricycles. As usual, Deshbhratar, Abhijit Gare, Vijaykumar Nalavade, Rajiv Vankudre, Ramesh Ranade and I were all there. We got to know the organiser of the camp very well.

But sometimes, simple matters have a tendency to get complicated, as I was to discover soon. One day, the camp organiser (whose name I will not mention), came to my office. He wished to invite my boss, the Assistant Collector, as the chief guest for his prize distribution ceremony and wanted me to accompany him to the boss’s room. Now, this organiser had given many devices and appliances to our children which obliged me to agree to his request. So I went with him to meet the boss with a special request that he must attend the function and be the chief guest. Saheb was quick to agree. He was happy with my work at the office and also with Helpers, extending me a helping hand whenever he could.

But one fine day, things took a different turn and I sensed that he was upset with me. I was baffled for many days. One fine day, he asked me why I was using my flat for commercial purposes. *Commercial?* I was taken aback. I was given a memo reprimanding me for “subletting” our official accommodation which was against office rules. So I produced my original application for the flat, where I had clearly mentioned the nature of my accommodation, which included my work with disabled people. The matter rested there for a few days.

In a few days I cracked the mystery of my boss’s displeasure with me and what emerged was quite horrible. The organiser

of the camp who I mentioned earlier and who had invited my boss to his function, was caught up in a departmental case against him. So he believed that inviting the Assistant Collector would help him get out of the mess. He even went so far as to visit him at his home at night to ask him to get him out of the case. Naturally my boss assumed that not only was I the organiser’s accomplice but had probably accepted a hefty donation for my liaison work! Incredible, but there it was. If I was asked to give an explanation I would have told my boss about what really happened right there in the presence of the organiser. These were unnecessary complications and I have always loathed them preferring, therefore, to keep a low profile in the accounts department with no special salary though I was considered quite capable in the technical department.

On another occasion, I had a showdown with the same organiser, who as I mentioned, supported our work by giving us artificial appliances. For some reason, he was dead against giving tricycles to persons who used calipers for both legs, believing that it was a luxury. But I had a different view. A certain distance can be covered on calipers, say, in half an hour. The same distance can be covered in five minutes on a tricycle. It is difficult to walk a long distance on calipers such as getting to school. We had several arguments on this point and finally I lost my temper and asked him, “Why, Mr ....., don’t *you* have good legs, why do you use a scooter? We can’t rehabilitate people just a *little*, it should be *total*. Instead of a hundred people, let us rehabilitate just twenty, but it should be total!”

I had enough reasons now not to attend his camps or even meet him anymore. He kept sending me proposals on how we could continue working together, but I was firm about my personal participation. Instead, Abhijit, Vijay Kumar or Rajiv who were now mature enough to take decisions on their own, took patients to his camp.

It was not just with the organiser, I also had to take up issues with our *own* members. Once NASEOH gave us several free tricycles and wheelchairs mostly for students. The tricycles were stored in a shed in the premises of the Central Excise Office. I was in a hurry to have the tricycles distributed since



I knew only too well how desperately disabled people needed them. I made this clear in a meeting.

"Oh no, let's wait for a couple of months, till we get a dignitary to do the distribution," said a member.

"Dignitary, what dignitary?" I was shocked. "It's not about dignitaries, it's about children who need them desperately!" I shot back.

"Naseema is right, how can we keep those tricycles in someone else's shed for so long?" said another member.

"That's not the point," I said. "It's not fair to keep the kids waiting for something they need so desperately."

It so happened that the Commissioner of Central Excise was to come to Kolhapur at that time.

"Let's get *him* to do the distribution rather than wait for someone else," I suggested.

But what a lady member said made me speechless.

"Aha! So you want to protect your career by inviting *him*!" she said, a sly grin spreading across her face.

"Hold your tongue lady, do you know who you're speaking to?" Deshbhratar lashed out. "You're talking to someone who has given her whole life to this work. Didi *has* a point, let the Commissioner see for himself how all our work comes out of *this* flat. He's our only safeguard against those in the department who complain about us every other day. Besides, you all know how Didi has to cut short her office hours in order to attend to Helpers' work. Let the Commissioner see for himself what we do and that's why she suggested that he be invited, not to further her career as you imagine!"

I was downcast. A fine accusation indeed against someone who never cared for a promotion or raise! There was a murmur in the gathering and finally the President asked the lady to apologise. She did so, reluctantly. Slowly, the atmosphere in the room cooled down.

We had many differences amongst us. For instance, once when we put up an event I proposed, "I think that one of our disabled children should present the guests with flowers. What our donors and well-wishers need to see is how one such child who couldn't walk earlier, can now do so after surgery, especially with the help of devices."

"That's all very well," said a member, "but have you thought about how ill at ease a guest is going to feel receiving flowers from a *disabled* child? Moreover, it's going to take time because the children walk slowly."

"Well then," some of us argued, "if they're going to feel awkward, they shouldn't be at one of *our* events in the first place! So what if the children take time to walk? Isn't the event meant for *them*? Our very purpose is to make them walk on their own. How ridiculous to say that we are 'wasting time' in order to achieve that!"

And then there were members who argued about who would sit where on the dais. They brought in all kinds of hierarchies—high and low, caste and community.

I have always been dead against the big show of distribution of things to disabled people through pompous ceremonies. To say the least, it is most humiliating. What earthly reason could they have to feel so except the sheer demands of their physical condition and their abject financial situation? But we discovered that donors wanted to see how and for whom their donation was used, so had little choice but to invite the public for some of our shows.

And worst of all, I had to *speak* on some of these occasions! I can do hundreds of things, but give me a mike and my hands tremble like a leaf! What a waste of time...I could do a million other things than make speeches. Babu Kaka pushed me to speak on the radio, but I was terrified. Once Mrs Meshram from Akashwani, Sangli, interviewed me for the radio after my award. When I heard the broadcast, I was a bit pleased with myself. It wasn't so bad after all, I *could* speak fairly well. Now, ten years down the line, I've overcome my fear of microphones and give public talks without my hands trembling. But if you ask me what I prefer, it's actual work and not speeches.

While on the subject of events, I recall another incident. Rajani and I wanted to keep a picture of Babu Kaka on a chair at the front of the stage as our way of paying homage to him. We wanted to put a garland of flowers on the picture and make him a part of our event. Babu Kaka was our inspiration and should share our success we believed. But some of our members objected to this saying, "Why should *his* picture be

on the stage? He is not the founder of Helpers. What is the connection? Remove it.”

The picture was removed from the stage at the last moment. Rajani and I kept quiet. Why should we make our differences obvious to the public? But then later we explained to the few who objected, that Babu Kaka had a very special significance in our lives, in fact, there would have been no Helpers without him. Since then he is a part of each of our events.

As our work progressed, we had to deal with more and more differences of opinion. There was the matter of the liquid soap, for instance. We were already selling foodstuffs and taking stitching orders. To supplement our income, some of our able-bodied volunteers began making liquid soap. The soap-making process was quite easy so I proposed that it should be made by disabled children instead. But the reaction to that amazed me, “*Disabled* children? Oh no, they’ll become too independent and leave the organisation. Let them do only the *selling* of the soap on a commission basis. We’ll keep the profits and use it to get ourselves a proper office.”

What profits? What commission? I just couldn’t understand. Were we not missing the point entirely? I presumed that the final aim of our work was to empower the disabled and make them independent. Here we were doing the contrary—we were forcing our disabled children to tell customers that they were the ones making the soap (in order to tug at their heartstrings). I decided to intervene. They were teaching the children to lie!

Around that time Ramakaki Shirgavkar and Smita Shirgavkar resigned from the committee. So we inducted PD and Shreekant Kekde. Deshbhratar was already in. Soon, as work increased, the seven-member committee became nine with the inclusion of Vinod Patel and Chhaya Desai.

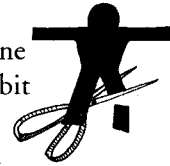
Chhaya Desai a medical student at the homeopathic college was brought by her mother to a medical camp to get calipers for her. At first Chhaya was hesitant to come to the camp and get the calipers for free. But her mother convinced her that it was more convenient to get it from here rather than making several trips to Pune or Mumbai for the same. After this Chhaya too got involved in the institute.

My sister-in-law, Irshad, my friend and helper, who was as involved as I, was a member of the committee.

Around that time I was given another award in Pune and Akashvani wanted a radio interview. I was a bit reluctant but Anutai and Sujalatai insisted that I give it. Anutai Bhagwat brings out an annual publication *Snehaprakash*, dedicated to the memory of her late father in which she highlights disability issues and Sujalatai Nitsure is a respected social worker. I was interviewed by Ushatai Page and it was broadcast a few days later. Young Ramdas Sonavne from Sangamner was one of those who heard the interview.

Ramdas had no father and his mother toiled hard to educate him. He was a graduate but had no proper job. Not happy with idling away his time, he worked as a daily wage labourer on a road construction site. Once he happened to be doing something under a concrete mixer. Suddenly the heavy tank of the mixer fell right on top of him. He broke his spinal cord and became a paraplegic like me. In one stroke, all his dreams of earning and improving his mother’s life were shattered to pieces. Instead, he became a small child again and his mother had to do everything for him. He was in the hospital for a year and was sent home after that. Ramdas’s life became one long saga of pain and misery. Thoughts of suicide and death were his constant companions. It was at this point in his life that he heard my interview on the radio. Some lady, in a town far away, was in the same condition as he was and was leading an active life. Clutching desperately to this only ray of hope, he wrote to me, “May I come to Kolhapur? Can your organisation treatment and rehabilitate me? I don’t have a single rupee. Even to come to Kolhapur I’ll have to collect funds from the villagers. Since I have a rod fitted in my spinal cord, I can’t travel sitting down. I’ll have to hire a special taxi so that I can lie down.”

“Oh God, What am I to do?” I thought to myself. “Why did I ever give that interview when we don’t have the wherewithal to look after those who responded to it?”



Publicising our work is all very well, but is it correct to raise hopes without being able to nurture them?" I was caught on the horns of a dilemma. We didn't have our own premises then and here was a man asking for care and shelter and we had none to give him. So I wrote to Anutai, "Here is a copy of Ramdas's letter. Let's say we manage to give him shelter, but what about the costs of his physical treatment? How wise was it to have given the interview?"

Anutai wrote back immediately, "I'm sending you two thousand rupees for the time being. We'll manage funds for his treatment too, don't worry."

Dear Anutai, always to the rescue. I was so happy!

Like Ramdas Sonavne, I wanted to help a little orphan boy, Prakash Joshi, with badly disabled hands and feet. What to do, I thought for many days. Finally I wrote to Ramdas, "Prakash is an orphan and can't find a home, no orphanage is ready to admit him. We will take complete responsibility for you and your mother. As an organisation, Helpers doesn't have enough funds, but I, as your elder sister, will take that responsibility for both of you. There is a condition, though. I would like your mother to adopt Prakash as her son."

Ramdas had to raise funds to come to Kolhapur and that took a fair amount of time. By then Prakash was discharged from the Mary Wanless hospital. Where should he go? He needed care, so a government orphanage was out of the question. Finally, PD requested Dr Pathak in Miraj to admit Prakash in his orphanage. Dr Pathak agreed and Rajani took Prakash to Miraj. Ramdas arrived the next day in a van and thus Prakash missed meeting his surrogate mother by a hair's breadth.

Ramdas came with nasty bedsores. I wrote to my uncle in Mumbai and got him a waterbed. Treatment began and he was in hospital for about two years. The rod in his back was removed and he was given a wheelchair. Soon Ramdas began to smile. We gave him a small job to do—he was to keep a record of expenses of patients (who belonged to Helpers) admitted in the same hospital. Food for both mother and son came from my home and I used my salary to meet their other needs. Every time I bought clothes for them their eyes welled up. They had no relatives; no one came to see them in hospital and they had no one to talk to. Ramdas was now completely rehabilitated

physically. A urine bag was tied to his leg, he could now wear a shirt and a pair of trousers and move around freely in his wheelchair. The same Ramdas who arrived looking like a skeleton with a lungi tied around his waist, was happy and active. It was something to be satisfied about.

But if there's one that I learnt from life is that it is an ever-changing process with a constant mix of ups and downs. One day we are happy and contented, the next we are unhappy and agitated. On one such tiresome day, I had a bad headache. I took half a day's leave and came home to rest. I took a pill and lay down. Within half an hour there was a call from the orphanage in Miraj.

"Ma'am, Prakash refuses to eat, it's three days now. He just keeps repeating, 'I want my Didi or I'll not eat.' Please come immediately."

Yes, I was guilty of not having gone to see Prakash even once since he went to Miraj. Balancing office and Helpers didn't leave me with very much time. But Rajani, every time she went to Sangli for her recordings, made it a point to drop by and see him in Miraj which was on the way so much so that the orphanage staff thought that Rajani must be the "Didi".

For all the time that Prakash was in Kolhapur he had never asked about his parents. But now he was sad that his Didi stayed away from him for a whole year. No, this would never do, I must set the matter right. I would get him to Kolhapur for a few days and introduce Ramdas's mother to him. She would be *his* mother too. I called a taxi and with Abhijit Gare and Neeta, headed for Miraj.

I was shocked to see Prakash. His condition had worsened, he was just skin and bones. He couldn't move his hand or hold up his head. From the minute he saw me he kept saying, "Didi, take me home." I took permission to take him home, especially since I'd seen the doctor's unhappy remark—Prakash was dying, I had to accept it. I called the Mary Wanless hospital in Kolhapur and told them, "Keep a bed ready near Ramdas's bed, I'm bringing Prakash Joshi." As always, Dr Satvekar agreed to arrange it. He never said no to anything we asked him for. However big his bill, he accepted only what we could pay, never ever asking for the rest of the money.

It was 30 December 1992. Our journey from Miraj to Kolhapur seemed endless. Prakash rested his head on a pillow on my lap. His head kept slipping and he moaned at the slightest movement. Abhijit and Neeta stroked him every now and then. We reached Kolhapur at midnight and went straight to the Mary Wanless Hospital. The nurse wanted to take him to the emergency ward but I asked for him to be put on a bed near Ramdas so that his mother could look after both of them. Prakash, who seemed to be in excruciating pain wanted to come home with me, so I said, "You'll have to stay here for a few days till you get better and then we'll take you home." Dead tired, we returned home at one. I ate something and fell asleep in minutes.

Next day, at the office, around eleven, I had a call from Neeta, "Didi, Ramdas's mother is here. Prakash is quite irritable, she says, and he wants you in the hospital."

A similar call came from Ma at lunch break saying, "Prakash is quite irritable and wants you."

I couldn't leave immediately, so I told them both, "I'm afraid it'll have to wait till four. I have something important to attend to."

But at three, Ramdas's mother landed up at my office, complaining, "Oof, that Prakash, he didn't let me sleep a wink last night. A real stubborn fellow that! You must come soon."

I was stunned. Was this woman human? Didn't we make our condition clear while accepting Ramdas for treatment? Didn't we take responsibility not only for Ramdas but also his mother? Mother! I could hardly use that word for this woman. She was a disgrace to motherhood. I was boiling with rage but controlled myself, saying, "You go ahead, I'll join you soon." By now I was used to controlling my anger, thinking calmly and then making a decision that best suited the occasion.

The first thing I did was to grab the file with the correspondence between Ramdas and me. Before showing the file to him I asked Ramdas, "What happened? Tell me, was Prakash *that* irritable?"

"Yes! Aai couldn't sleep at all. He was complaining all night, 'Turn me this way, I have pain here, I have pain there' and so on!"

Overcome by pure anger now I asked him, "Why Ramdas, did you not bother her the same way when *you* were ill? Was she irritated then? Well, your mother can get her night's sleep now, we won't depend on her to look after Prakash, that's for sure."

I asked for Prakash to be shifted near some of our other patients. I was so desperate now that I literally caught hold of a girl who was looking after her brother who had a wound on his leg. The wound wasn't healing and was oozing for several months. (This brother had a history—he had once manipulated some bills while working in Helpers and appropriated some cash). So I had little compunction when I told his sister, "You better take care of Prakash or we'll send your brother home and he can come here twice a week to get his wound dressed." She nodded desperately, fearing that her brother's wound would never heal if that happened.

Prakash couldn't control his urine or bowels and the sheets had to be changed constantly. I brought some sheets from home and changed them myself. Abhijit, Rajiv, Ramesh—all of us took turns with Prakash. We gave him whatever he asked for—snacks, toys. That was the only thing we could do. The pain drove him mad, but all we could do was caress him and dust his body with talcum powder.

He once asked for an aeroplane. He couldn't even hold it in his hand so we placed it near him on his bed and he put his hand on it. "Come Didi, let's fly to Delhi," he smiled. All he wanted to do was go home with me. He said it every single day. After a month of this constant request, I sought the doctor's permission. He was visibly angry with me, saying, "We know you love the child, but there's a limit. How can you take him home in this condition? The answer is no."

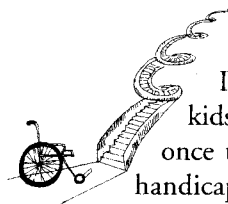
One of our senior patients had a bed near Prakash's. He started to feed Prakash and clean his bed. Prakash called him "Uncle Sheikh." Really speaking he was playing the role of Prakash's father. I wondered how on the one hand, a cold and selfish able-bodied woman rejected Prakash and how on the other, a childless disabled old man became Prakash's adopted father. I had to accept both situations for that was life. For one month I could not concentrate on my office work or Helpers. It was Prakash before work and after work. What I could do was only to return home at night and sleep. I was in

a peculiar state of mind where I found myself praying, "God, take Prakash quickly, painlessly."

Once Prakash said, "Didi, take me out in the open." But how was one to do that? He was totally crippled. But Deshbhratar and our children managed somehow. They took turns to spend the nights with him. The end was nearing. On what we guessed would be his last day—30 January 1993, they made me go home because they knew it would be unbearable for me. I was taken to the hospital, late at night, only after he had died. Poor child, he died an orphan. Still I thanked God that Prakash was put out of his misery.

Despite the lateness of the hour, I found that many people from Helpers had gathered for his cremation. Even Anant Dixit, Editor, *Sakal* was there. We all went to the crematorium and performed what was to be Helpers' first last rites. I watched our young boys going through the motions precisely and with dignity. How could these young boys know so much? God only knows whether Prakash (whose name meant "light") went from light to darkness or from darkness to light.

Since then, whenever I saw vast tracts of unused land in this vast country, a knife twisted into my heart. I thought to myself, "With all this land available, why can't our disabled children have a house for themselves? Why didn't *Prakash* have a house he could call "home"? Each day, I became more and more determined that the many Prakashs, who would no doubt follow in the future, should not be homeless. This would be our next mission.



In government run homes for disabled children, kids are normally sent back to their villages or towns once they turn fourteen. Also they don't admit severely handicapped children as it may require the employment of special staff to take care of their needs. Really speaking, these homes should be (re)named "Homes for Slightly Disabled Children who can Manage Everything on their Own" so that one has little or no expectations of them. Until they are fourteen, the children are operated on, given artificial devices and money is spent on them. But on that fatal day



when they turn fourteen, they have to leave even if they are still in class seven with no recourse to further education. Let's say, even if parents then decide to send them to a "normal" school, the buildings are not disabled friendly. So what happens? These kids remain under-educated. Every year several intelligent children are deprived of an education beyond class seven. So Helpers decided—we shall build a hostel for disabled kids so that they can stay there and attend school. It was an ambitious plan but we rolled up our sleeves and began to look for land.

Land—that meant government, so the first thing was to submit a proposal. We had been applying to the government for land (which we assumed was vacant) for many years ever since the inception of Helpers, but were told each time that the land was "already allotted." So how does one know *which* land to apply for? Ajit Kumar Jain happened to be the District Collector then. Though we hadn't yet invited him for any of our functions, we invited him to come to our office on a holiday. He not only came but listened very attentively to what we had to say about our work and our plans.

"A *hostel* for disabled children? But can you possibly undertake such a *huge* project? Why not join hands with some other organisation?" he was skeptical.

"You see Sir," we explained "we are disabled people needing a particular type of construction and facilities. It's difficult to find another organisation which would respond to those needs very sympathetically."

"Hmmm....I see your point. I'll do my best." I believe he did see our point.

"Sir," we told him as he was leaving, "can you give us an idea about the location? We seem to be constantly applying for the wrong land!"

"Come to my office tomorrow. No, no, I don't mean come yourself, you can send someone," he said.

He told us about a certain vacant lot so we applied at once. And lo and behold, for the first time in years, our file moved to the Secretariat in Mumbai with a special recommendation from Jain.

The lot was in a place called Uchgaon. A polytechnic was under construction in an adjoining plot of land. No sooner





had we set our eyes on that building than we began to dream. A polytechnic would have students, students would need food so we would run a canteen and perhaps even the mess. Thus we would be able to meet our food expenses and so on and on.

A few days later, Deshbhratar and I went to the Secretariat in Mumbai. As in the case of most government offices, we needed an entry pass but I had a wheelchair and no pass. So I called the Under Secretary in the Revenue Department (we had no idea who he was) from the gate and told him that we needed to enter and would he kindly allow the wheelchair in. To our utter surprise, he sent a runner boy to us with the gate passes.

We discovered that five other organisations had applied for the same land in Uchgaon. It was a large piece of land but we asked for only two acres though we were advised by friends to ask for five. But there was a rule—you had to have a ready bank balance that amounted to at least one-third of the total expenditure of your project. The estimated cost of our project was forty-four lakhs. We planned eight rooms to accommodate eighty students, a kitchen and a dining hall. Just for this bare minimum we needed to show a balance of five to seven lakhs. A project on a larger piece of land would require an even larger bank balance. But we tried hard to get at least two acres.

We went to the Secretariat again to see Chagan Bhujbal, the then Revenue Minister. We'd already gone there twice but couldn't meet him. His Personal Assistant told us that he was at home and was about to leave Mumbai in a short while. My nephew, Zafar, who was with me, did some quick thinking. It was a race against time. He hailed a taxi, hauled me into it, folded my wheelchair, got in himself and told the cabbie to rush. It was probably a foolhardy exercise (the minister was most likely on the road already) but we *had* to try. Somehow this seemed easier than going back to Kolhapur and coming again to Mumbai. We reached the minister's bungalow. As luck would have it, there were those infernal steps again, so Zafar left me at the bottom of them and ran up. Suddenly,

Mr Bhujbal came out from another exit and saw me. He wanted to know who "the lady" on the wheelchair was. I introduced myself and gave him a quick briefing and also showed him our collection of photographs on our work.

"I'll help you," he smiled. I was delighted—the rush was worth it after all.

Zafar didn't meet the minister obviously, but I sensed somehow that our mission was complete.

It turned out, when I returned to Kolhapur and told Rajani what happened, that the minister was an ex classmate of hers. Great news! She wrote to him referring to my meeting with him. And just a few months before Mr Bhujbal stepped down as Revenue Minister because of the new elections, he approved our proposal. The land was ours and so were our dreams! Mr Bhujbal, we will always be grateful to you.

The land for the hostel at Uchgaon was granted to us. However, as I mentioned earlier, to get the land officially transferred in our name, we had to show a bank balance equivalent to one-third of the project cost. We had collected some donations for the hostel but not enough.

Around the same time, our application to run a gas agency was approved. Indian Oil, the supplying principal, had a rule that we had to open it within a year of the sanction. Since this deadline was fast approaching, we had diverted the funds collected for the hostel to the gas agency for acquiring land and constructing a warehouse and purchasing a showroom. Now this amount had to be hastily transferred to the hostel account.

Since the gas agency funds were now depleted and with the deadline hanging over our heads, we thought of taking a bank loan. For this we needed the approval of the Charity Commissioner in Pune.

Vinod Patel was one of our committee members doing his chartered accountancy in Pune. We entrusted him with the responsibility of getting this approval, which he did. Armed with this, we approached several banks for the loan. Finally, the Ratnakar Bank agreed to give us a loan of seven and half lakh rupees. All the committee members had to go together to the bank to sign the documents. We had to do this urgently since there were only three days for us to show the requisite amount as our bank balance and take possession of the Uchgaon land.

All our committee members were in Kolhapur except Vinod Patel who was studying in Pune. We informed each of our members of the date on which we were to go to the bank

together to sign the documents. We asked Vinod to come a day earlier to avoid any delay.

"We must go and get Vinod or we won't get the loan," PD called me on the phone when there was no sign of him till noon the day previous to the signing.

"He does suffer from asthma, doesn't he? He must be seriously ill. It's most unlike of him not to call and inform us," I surmised.

"Well, only you can get him then," PD said.

There was no alternative but to take a taxi to Pune. Arun Lokhande our technician at the training center, who had a lame foot but still managed to carry me, Vishranti and I were on our way.

"We'll get him to Kolhapur in a taxi and drop him back in the same taxi if he's sick," I told the others.

At midnight we were knocking on Vinod's door. His father answered the door but didn't ask us in. Strange, I thought. Soon, Vinod appeared at the door too.

"My son will not have any part in signing the loan documents," the father announced without much preamble.

My jaw fell open and my face must have paled, "Bu...bu...but Dr Mohanrao Gune, who you know is a respectable man, and my brother Aziz have agreed to stand guarantee," I stammered. "If we are unable to pay, the bank will recover the loan from *them*."

"I work in a bank myself and I know all about these things. I don't want my son to go bankrupt," the old man stood his ground.

All this while Vinod stood listening. I faced him squarely, "Listen, you are not a minor. You can take your own decisions, can't you? Do you agree with your father?"

No answer.

"Why didn't you at least call us?"

Still no answer.

I tried another tack. "Look, in case we fail to pay up, I will personally take responsibility for Vinod. I can give this in writing on a stamped paper. But please come with us, we have no time to lose."

Still no answer.

"Okay, in that case, we need your resignation," I said

He wrote out his resignation and I said, "Let's go." We hastened back without even a sip of water.

Back inside the taxi, I was mad at what happened. How could Vinod do this? Wasn't he disabled himself? The problem was that he wasn't poor enough to need a hostel for his education. He was rich. We were all distraught and to top it all, our taxi broke down! By the time we reached PD's house, devastated and disheartened, it was five in the morning.

Meanwhile, not having heard from us, PD gathered that Vinod was not coming back with us. Within the span of the same night he managed to raise three lakhs from his friends and Deshbhratar raised four lakhs from Jayavantrao Joshi. Hastily, we passed a resolution about Vinod's resignation, reached the bank by eleven and deposited the cheques. The bank gave us a statement immediately and we took possession of the Uchgaon land. Within ten days we got another loan from the Ratnakar Bank and repaid our donors. It was only because of their implicit trust in us that a hundred children now live in the hostel today.

It was a Sunday and we were busy working. Suddenly PD came in with shocking news—Madhav, aged fourteen, a student of class nine, was having fun at a house-warming ceremony at his uncle's house. He was playing on the terrace and tried to remove a kite from an electric pole with an iron rod. A terrible shock wracked his body. Both his arms and legs were charred to ashes. He was rushed to the hospital but developed gangrene. There was no option but to amputate both his arms and legs. I hate to say this, but Madhav looked like the bust of a statue. He would need a wheelchair and luckily for him, Sharfuddin Kapdi of the Mera Hotel had given us a nice imported wheelchair just a week ago and we gave that to Madhav.

For eight whole days I had to muster up the courage to see Madhav. I shuddered to even think about his condition. Yes, God and the doctors had saved his life, but for what? The orthopedic doctor at the hospital told us, "Nothing can be



done. His arms have no stumps nor his legs, so we can't even fit him with artificial limbs."

It so happened that around the same time, there was a conference of orthopaedic specialists in Kolhapur. Dr Chaubal, an eminent doctor from Mumbai was part of it.

Dr Gajanan Jadhav, whom we knew well, helped us get an appointment with Dr Chaubal. Though Deshbhratar and I reached on time, there was no Madhav in sight, so he had to go in a rickshaw and bring him. I was a bit irritated—we were going to all this trouble for the boy, why was it that his mother or uncle couldn't bring him in time?

Dr Chaubal said, "There's not much that I can do given how damaged his limbs are. But I see hope if the All India Institute in Mumbai takes up Madhav's case as a challenge."

We thought it best then to take him to Mumbai. But again, what about money? Ma and I pulled out some money from our respective accounts but that wasn't enough. Around that time, I'd introduced myself to Kamalabai Sovani, a ninety-year old freedom fighter and donor, who lived in Ogalewadi, by letter. Mr Thakar, who worked with leprosy patients, had given me her address and asked me to write to her about our work. I wrote to her about Madhav and our need for money to have him rehabilitated. She sent us a sum of money. A prominent newspaper carried an article about Madhav, urging the public to contribute. The response was good and money came in. Every small effort counted—I was reminded of the little squirrels who made a bridge over the ocean to let Lord Rama make his way to Sri Lanka.

It is worth mentioning here that the lepers of the Swadhar Kendra (many of whom begged for a living) donated five hundred rupees. They said, "We don't have fingers, it's true, but we have arms and legs. Poor Madhav, so young, what's he going to do? Here is our donation, we'll send the money to you."

"No no," we said, "we'll come and get it ourselves." Like most lepers, they thought no one would like to visit them. But their kindness was worth a lakh of rupees! Shivaji Patil, Deshbhratar, Rajani, PD and myself went to the leprosy institute along with Madhav. Surrounded by such kindhearted, generous people, blighted by such a wasteful

disease, Rajani and I broke down. PD, ever the one for propriety, warned us, "Ladies, ladies, you must control your emotions in public places."

PD was a one in a million person. He was always pleasant and mild-mannered. However worried or agitated I was, I always cheered up when I heard his soothing voice over the phone. There was a time, once, when I almost thought of leaving Helpers, upset by some unpleasant turn of things. But PD consoled and cajoled me, "You've already left an organisation once, you can't leave *this one* too. Let those whose aspirations are different, leave. You have our support, so be patient." With his wonderful calm and negotiating skills, he finally turned our wavering organisation around. PD is one of our biggest supports. So Rajani and I humbly yielded to PD's quiet chiding and wiped away our tears. Yes, we would control ourselves in public places we assured him.

Deshbhratar and I left for Mumbai with Madhav to admit him in the All India Institute. Madhav's uncle couldn't get any leave so Deshbhratar had to take leave from work instead. Whenever I travel I need two people to take care of me—a male helper to lift and carry me and a female helper to take care of my personal needs. Madhav's mother was travelling with us. Since Deshbhratar and I had taken leave from work just for Madhav, I assumed that his mother would be kind enough to help me just as she helped Madhav. I was finding it increasingly difficult to travel in a second class three-tier coach except when we were a group of six. Ma had stitched a special curtain to cordon off that section, since I needed privacy for my personal toilette. But when we were just a couple of people, I usually travelled first class since the compartment had a door.

Madhav and I were waiting in our wheelchairs at the station. A passerby stopped in front of us. He said that he had read the article in *Sakal* requesting donations for Madhav's treatment. He too wanted to contribute his humble share of twenty-five rupees. I felt a bit awkward accepting the money right there on the platform but I also felt that I needed to respect *his* feelings. I noted down his name and address. I imagined that Madhav would be embarrassed about this. I couldn't help recollecting the

horrible nightmares I had when I first became disabled. I dreamt of passers by, overcome by pity, throwing coins at me by the roadside. I would wake up in cold sweat. So I casually asked Madhav, "How did you feel when the man gave you the money for your treatment?"

"Why? I felt quite happy!" he replied.

I was sixteen when I became a paraplegic, Madhav was only fifteen. Maybe he needs another year to mature, I told myself.

The *Sakal* article brought in a good response. But we got to know that many donors, instead of sending their contributions to Helpers, gave money directly to Madhav's family.

Suddenly we discovered that now two of his uncles were going to accompany us to Mumbai. I wished they had told us earlier so that Deshbhratar needn't have taken leave.

We had a difficult time trying to lift Madhav from the wheelchair and seat him on the train. Deshbhratar always lifted me by hauling me up under my arms, but Madhav had no arms therefore no armpits. But Deshbhratar managed to do it somehow with the help of others. Madhav's uncles, who had earlier refused to come to Mumbai under the pretext of not getting leave, were now ready to go because they were flush with money. Nor did they inform us till the last minute.

The train caught speed. I was angry with the family but said nothing. Madhav chattered all through the journey saying this and that, "I like non-vegetarian food. Will I get some in Mumbai?" and so on. I had hoped Madhav's mother would help me with my personal needs, but not only was she most unhelpful, but Deshbhratar had to step in, much to my embarrassment. By now I'd learnt that often, parents of disabled children are not very helpful towards other disabled people. This is something that really troubles me.

Madhav's uncles were of no use at all in Mumbai, turning out, instead, to be more of a bother. We usually had our breakfast at the All India Institute canteen. At such times we prefer to order simple and inexpensive food. But Madhav found it distasteful and ordered something else. His mother didn't seem to mind.

Mrs Fernandez, the social worker, who already knew about us, assured us that she would find a donor for Madhav's prostheses. We shouldn't be anxious, she told us.

Before heading back for Kolhapur, I explained to Madhav's mother that my uncle Haroon, who lived in Mumbai, would arrange for their return train bookings once Madhav was discharged. I was shocked when he suddenly piped up, "Don't we get concessions for air travel? There's a flight from Mumbai to Kolhapur."

God had been unkind to Madhav and I thought it best, therefore, to control myself all along. But now something snapped in me and rage welled up. I was doubly furious with his mother who seemed to be encouraging him. I burst out, "Have you come here on a picnic? You're here for your treatment and that too with the generous support of several people. How can you keep thinking of luxuries? On the contrary, you should be thinking, 'I'll repay (and with interest) all the money given to me.' Your mother earns three hundred and fifty rupees per month. The remaining expenses have been borne by Helpers and society at large. How can you think of air travel, luxurious breakfasts and mutton and chicken all the time? Yes, we travelled first class because I couldn't travel in a three-tier coach and besides, I would've been uncomfortable travelling first while you were in second class. But mind you boy, you will return by second class! You and your mother shouldn't capitalise on your disability, that's downright cheap! I never even think of air travel when I'm on work."

Both mother and son didn't expect this from me and were speechless. They started crying. I felt bad but I had to let them know. A few days later, Uncle Haroon told us, "These two are very smart, Naseem. When rich visitors come to the hospital, they tell them, 'We're all alone,' never once telling them about the financial support given by Helpers." Naturally, given the way he looks, Madhav wrung pity out of everyone and they gave him money.

Madhav was very sharp. He went through his treatment meticulously. His determination was undaunted and soon he stood up on artificial feet. He was offered a wheelchair as a gift but refused to take it thinking that we might take back



the good imported one that we'd given him earlier. At the very least, he could have taken it and given it to Helpers to help at least one more disabled person who was in dire need of a wheelchair. Well, that was Madhav, selfish and inconsiderate. There was no use talking to mother and son anymore.

But his iron grit to improve his lot was amazing. Madhav began to write with a pen in his mouth and kept us informed about his progress. He wrote beautiful letters. Our hard work had paid off and I was happy. Madhav returned to Kolhapur and started attending school with the cooperation of the school management. Helpers paid his rickshaw fare to go to school and kept aside a deposit of five thousand rupees for his future. Madhav gave all his school exams, writing the papers himself with a pen in his mouth. He refused to get himself a "writer" for his final board exams but we knew that he couldn't hold out for long and insisted he get one. He passed with seventy six per cent marks, a commendable achievement indeed! For the people of Kolhapur, Madhav was the wonder kid and they heaped him with honours. For a child with the most horrific disability, he never lost heart once. Helpers too gave him the Bharari award, which meant "The Great Flight."

But just as his brilliance was awesome, so was his self-indulgence. Once, he needed new clothes, so we gave him money and asked him to give us the shop receipts. When we saw the receipts we were speechless. Madhav's mother had bought clothes from Dreamland, Kolhapur's most expensive shop! Neither PD nor I, though we earned well, ever bought anything from there. These two were impossible!

I was amused to see society's inexplicable responses to things. When Madhav needed money for his treatment, help was meagre. But now that Madhav was successful, they showered money on him. If only they had seen him when he most needed help.

Once we took Madhav with us to Delhi and Agra to see the Taj Mahal. But Madhav being true to his nature, not only borrowed from the other children, but was pre-occupied with how to get mutton for himself while the rest of us were worrying about how to get inexpensive food!

Most disabled people in villages and small towns are unaware that there are government schemes that provide certain facilities and concessions especially for them. For instance they could get special passes for state transport buses and trains.

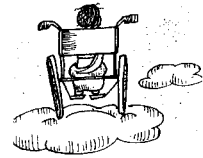
So, not only was it important to inform them about these concessions, but it was also necessary to empower them to actually avail of these passes by way of a medical certificate issued by a bona fide doctor. With this in mind we fixed a date with the civil hospital (Dr Pathak was the orthopedic consultant then) to organise a camp for medical examination and certification.

Sujata Kulkarni, disabled by polio, was a volunteer in one of these camps. Most of the time we were very short of people, so sometimes we had to resort to enlisting some of our patients or even their parents for various assignments. So when Sujata joined us we were thrilled. Now there were three—Vankudre (polio in one leg) and Nalavade (polio in one hand)—to combat the ever-increasing workload.

We gave Sujata a small stipend of a hundred and fifty rupees. Her polio-legs were so bad that she teetered when she walked and I was always afraid that she might fall. I've often wondered how she even managed to walk the distance from the KMT bus station to my house. But she smiled a lot and I loved that smile! But at the slightest scolding she would burst into tears, and that made me feel bad. Now we're kind of used to each other—her smiling, my scolding, her crying and then smiling again. As time passed, Sujata's condition worsened and by now she couldn't walk without support or commute by bus.

Like everywhere else, one had also to constantly deal with murmurs of discontent. Like the complaints of Tanaji Bhivsekar (who had polio in one hand) and Neeta who both told me, "Didi, what does Sujata think of herself? Who is she to sit in one place and give orders, 'Pass me this, pass me that?' We're fed up!"

Seeing Sujata's condition, I was often tempted to allow her the use of a wheelchair. But then I remembered Dr PG Kulkarni's words, "Didi, don't allow those who can walk to use the wheelchair."



“Look,” I had to explain to Neeta and Tanaji, “If we at Helpers can’t understand *Sujata’s* problem, then how can I expect *the world* to understand someone like *me*, bound as I am to my wheelchair?”

Sometimes, work so overtook me that I didn’t even stop to think how little I was communicating with my colleagues and how misunderstandings were rife therefore. For instance, I didn’t realise that “the boys” had a serious grievance against Neeta and Deshbhratar, going so far as to say that they were actually obstructing the progress of Helpers. What was the allegation?

As I’d mentioned earlier, we supplied foodstuffs on order to various organisations. Sometimes the raw materials remained unused. Since they would go bad and since I disapproved of waste, I’d told Neeta to pay for them and take them to her home. Now Vankudre, Abhijit and the others believed that the Deshbhratars were *pilfering* the stuff! And not just that, they found them too fastidious about cleanliness and discipline which got their goat!

But then, I gently told the kids, “Listen boys, I don’t think you understand them. The Deshbhratars, though they tick you off at times, love you more than even I do. I don’t suppose you know that they often spend from their own pockets just for you.” I had a nice chat with the boys and cleared the air. Vankudre, who led the “mutiny,” was creating several rifts among the workers. This was becoming the norm with him, stirring up the others against this person or that, or this matter or that. I didn’t want Helpers to go the mutinous way of other organisations so we had no option but to remove him gradually.

Since we had many boys and girls working with us we had to deal with problems often sexual in nature. Unfortunately the parents of these kids vested with me the unwelcome burden of being a “guardian” of their characters, so I became this stern moral figure much to my own displeasure. But nevertheless, I had to be particularly watchful of disabled girls who were too easily led up the garden path and before long found themselves in trouble, both emotional and physical.

Take the case of this young disabled girl who used to come on Sundays ostensibly to “help out.” Helpers had facilitated a surgery on her leg. After work we all left for home,

but she hung around and went out with one of our boys, Rajiv, to a garden or some such place. I thought it best to keep her mother informed about this, but she seemed to have no complaints about Rajiv. We would have preferred them to first complete their education, get a job, be independent and then marry. Scandals wouldn’t be the best thing for Helpers since we were a public institution, accountable to the public as it were. But the two continued their dalliance and it seemed that the girl was on the brink of landing herself into a compromising situation. We had little option other than to close our doors on them.

Principally, we never have any objection to girls and boys who like each other and wish to marry. In fact, we encourage it so that disabled people have an opportunity to set up their own home, live normal lives and have children. So we set up a “marriage bureau” and Rajani took charge of it. I wanted to have nothing to do with this project but PD and Rajani pushed me into playing a part in the *vadhu-var-mela* (the bride-bridegroom function) which was organised in the Chandvani hall.

I thought it would be a happy and peaceful affair, but to my horror, oh God, some of those proposals were directed towards *me*! I was already receiving many proposals of marriage. Perhaps my job, my salary, my flat and the fairly well off position of my brothers were attractive features. But at the function there were more proposals. I’d never wanted to marry and this was the last thing I wanted to deal with. So when one of those “proposals” became very persistent and annoying, I said enough was enough and removed myself completely from the marriage bureau project. I told Rajani to run the bureau from her home and not from the Helpers office. And so ended that embarrassing saga.

Once we had to deal with a complicated case which took an altogether different turn. One of our young boys was very friendly with one of our girls. He didn’t heed our warnings and sure enough the girl got pregnant. She was distraught and came to me weeping, “Didi, I’ve nowhere to go, I must die!” What was I to do? I felt sorry for her and despite a big forthcoming event at Helpers, Deshbhratar, Rajani and I went to Narsoba Wadi and got the two of them married. But to



our horror, the boy's parents rejected the "disabled" daughter-in-law and were very clear that she would not be welcome in their family. How could they do this? Wasn't their son responsible for the girl's pregnancy? Rajani made some temporary arrangements for them. I persuaded Desai Kaka, who was in Kolhapur to attend our event, to meet the boy's father and convince him. But not only did the father not accept the pregnant girl as his daughter-in-law but said that he would find another girl for his son from his own community. We had failed miserably.

So they decided to set up home independently with a little financial help from me. But they used the money for an abortion though it was risky for the girl. The girl's mother didn't want them to have a child that came "too early" after their marriage! I was too horrified for words, but since I had little choice in the matter anymore, I decided to forget the whole unhappy affair.

I had moments where I held myself responsible for such happenings and had many self-doubts. Could it be that I couldn't instill some sense into these kids? These children were with me from a very young age. What went wrong? "Well," I consoled myself, "not *everyone's* life gets complicated like this so maybe I shouldn't worry. In fact I should think of those we *have* been able to help in whatever way."

Like Ramdas Sonavne the paraplegic who heard my radio interview in his village and came to seek our help. Now he was rehabilitated and ready to strike out on his own. But where would he stay? My elder brother, Bhaijaan, had a flat. We leased it from him on a small rent and started our training center. Ramdas would stay there. What next? We thought that it would be a good idea to give Mr Sadashivrao Mandlik the MP, an application on behalf of Ramdas. We wanted that he should be given the post of "Gramsevak," a village social worker, in the Zilla Parishad. Ramdas was called for a written test for which he had to go to Pune. By now I was used to travelling and staying out, but how would he, a paraplegic like me, manage? I asked Sujalatai in Pune if she would keep him especially since she had a European-style toilet in her house. She agreed. So Ramdas went to Pune and gave his exams. He passed, got a job soon thereafter and was given an

appointment letter but the Zilla Parishad people raised an objection. How could a Gramsevak be on a wheelchair? No, that wouldn't do.

"Why not?" I was mad and told myself that Ramdas would get the job if that was the last thing I did! I spoke to his boss.

"Hurrah!" I thought to myself when Ramdas got the job. He, a pathetic paraplegic, was now *completely* on his own!" At the village he was given accommodation in a large house in which only he and his mother lived. They invited me for dinner and when he got his salary he bought me a sari. I normally don't accept gifts but refusing him would mean that I did not share his joy.

Ramdas gave a public interview on 5 April 1994. This was what he said:

"I am Ramdas Hari Sonavne from Savargaon, Sangamner in Dulia District. Though I was extremely poor, I went to school and got seventy-five per cent marks in my SSC examinations. Then I did a diploma course in agriculture from the Mahatma Phule Krishi Vidyapeeth and passed with seventy-two per cent marks. Because of the zero budget policy (that is when there are no vacancies for government jobs they stop recruitment for some time) there were no openings for government jobs. So I tried hard to get private employment but without any success. I had no option other than to work as a labourer to sustain myself. Friday, 30 June 1989 was the unluckiest day of my life. While I was working at a road site construction job, the biggest and heaviest part of a concrete-making machine collapsed on my back. That very instant I went limp waist down. Just nineteen days after that, on July 19, I received an order of appointment as Gramsevak in Nagar from the Zilla Parishad. But how could I now take up any work? I had joined the ranks of the disabled. My contractor and some of my relatives helped me for several months to get myself treated in Pravaranagar and Pune. But I could do nothing except lie in bed. And then followed the most abject depression where I drowned in nothing but darkness. I was hardly a human



being and my future was written off. There was nothing except a black pit.

My life went on thus for sometime. On 7 March 1992, I switched on my radio to Akashvani, Pune, as I lay enveloped in bleakness. There was a lady speaking, giving an interview. It turned out to be Naseema Didi, President of Helpers of the Handicapped. I noted down her address and soon I sent her a letter telling her all about myself. And then I got a reply! My mother and I were to go there immediately. But where was the money for travel? My friends and relatives stepped in again and managed to collect some money and on 4 August 1992, I made my arduous journey to Kolhapur and Helpers. Didi took me to Dr Satvekar at the Mary Wanless Hospital. I was admitted and my treatment began.

My most precious memory as I was going through the difficult treatment was the boundless affection of the people at Helpers, both office bearers and volunteers. I was in a different town, four hundred kilometers away from my village, in a strange hospital, going through a hard time, but because of these friends, I hardly missed our home. Watching Didi was an experience in itself. For the first time I realised that disability need not stop anyone from helping other disabled people. It seemed possible for me to become human again and gradually, my confidence picked up.

Didi saw how poor we were and arranged for our meals, clothes and so on from her own pocket. How can I ever forget this? Amazingly, even her family people treated us as if we were part of the family.

The success of my surgery was a combination of financial assistance from Helpers, their kindness and, of course, Dr Satvekar's skills. The rod from my spine was removed and I could sit on a wheelchair gifted to me by Helpers. There was no back pain now. Completely bedridden as I was just a few months ago, I could now move around! Around that time, we saw another advertisement for the post of Gramsevak. My application was filled in and sent to Pune.

I was discharged from hospital in August 1993. My physical rehabilitation was nearing completion, but I

was still a social misfit, unable to earn my keep. It was time for me to be self-sufficient. Mother and I were allowed to live in Didi's brother's flat which was used as a vocational training center. I started working at the Helpers gas agency, noting down the names of new customers. I was getting used to some form of work, however small.

On 16 September 1993, I was called for an interview to Pune for the post of Gramsevak. Helpers gave me an assistant and thanks to Didi, I stayed with Sujalatai Nitsure who looked after us very well. I did well in my interview. Didi, Deshbhratar Sir and PD Sir personally met Sadashivrao Mandlik, the MP, to push my case further. Everything put together must have worked for I was appointed Gramsevak at Shenda Park in Kolhapur.

So now I had a job but there were still more things that I had to tackle. Where was I to live, for instance? As an initial step, and on Didi's recommendation, Mr Devalpurkar, a leprosy home social worker and a close acquaintance of Didi, gave us a part of his house to live in though it was really small, a gesture I can never forget. I joined work on 18 October 1993. Dr Bhomaj, Supervisor of the Kushthadham (Leper's Home) in Shenda Park took note of my disability and arranged a government accommodation for me. What can I say? Luck seemed to play a major role.

Thus Helpers of the Handicapped completely changed the course of my life which would have otherwise rotted away in my bed. Above all, I learnt self-respect and confidence. Isn't it my duty to help the organisation? Yes, I say, yes!"

Thus ended Ramdas's public talk.

One day, as I was at work, Ramdas's mother rushed to me, anxious and breathless, "Ramdas is unable to pass urine. We've taken him to Dr Satvekar. Please come!" I closed my files, took my boss's permission and left for the hospital.

Dr Satvekar quickly arranged for Ramdas to be taken for an X-ray. Ramdas had developed stones in his bladder and had to be operated upon immediately. Deshbhratar was there too.





The next day, we took a medical certificate from Dr Satvekar and a leave application to Ramdas's office since he would be absent for one or two months and that too so soon after joining work. We requested his boss not to put any adversary remark on his papers and not to take another person in his place. Ramdas was fortunate to have a kind boss.

Ramdas was better after his operation and completed a year of work. He donated half of his first salary to Helpers and then donated hundred rupees each month. And soon, when Ramdas was well settled, the relatives began to appear. How come no one turned up at the hospital where he was admitted for more than a year? I guess relatives don't appear at critical moments!

Once I was away to Delhi on work. I had no idea that something horrible was about to happen. It was near Diwali. Ramdas's sisters invited him for Diwali and he took leave from work. Had I been there I wouldn't have allowed him to leave Kolhapur because his condition was still fragile. On the contrary, I would've told him to invite his sisters over to where he was. One fine day, while I was still in Delhi, I received a telegram—RAMDAS EXPIRED. What! I couldn't believe it.

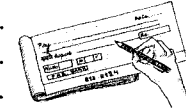
It happened like this. At his sister's place, Ramdas developed a fever. His feet swelled up and he died within two days. It was urine infection, the bane of paraplegics, and I knew how deadly that could be. Five or six paraplegic patients before Ramdas whom we treated, had died within some eight months of going to their villages. I thought Ramdas knew about this.

I asked myself again and again, overcome with grief at Ramdas's passing, "How come, I, a chronic paraplegic am still alive? And why?" This was something that preoccupied me ever so often.

I tried hard to forget Ramdas by throwing myself into work. And every time we treated a paraplegic, I couldn't help thinking, "We work so hard, spend so much and then they die and I'm still alive." What was it that I felt sorry about? Their death or my life? I have no answer.

The government gave twenty five thousand rupees to Ramdas's mother as compensation. She still sends in her donations to us.

We began receiving donations from many people. One of them was Dr Manjiri Nimkar from Phaltan. Her donations were used for surgeries and devices.



As in most cases, Helpers too had to deal with inter-institutional politics and bottlenecks. Once, before our training center became operational, we placed an order for calipers with an organisation in Belgaum. We didn't get them. On enquiry we were told that their calipers technician was about to leave and go abroad but that our job would be done before he left.

In the meanwhile, NASEOH was giving us free tricycles and wheelchairs for the past two or three years. The most important (and tedious) thing was paperwork which harangued us no end. We had to fill in their prescribed forms of application and provide annexures like income certificates, medical certificates, photos and so on. The Belgaum organisation too had sent in their applications but never got any positive response. So once when I was going to Mumbai on work, the Secretary of the Belgaum organisation, who was also my friend, requested me to recommend their case to Nama Bhat of NASEOH. I spoke with Nama Tai. She was very clear, "Naseema, if *you* are a member of that organisation and they give *you* the authority to sign their applications I'll approve. We just can't waste time or money on those whose applications are not complete. These are government grants and we have to follow procedures. We can't spend so much time on correspondence. Besides, we have to submit accounts on time."

I had always been meticulous about submitting complete paperwork and Nama Tai therefore felt confident about me. That was all very well, but I wasn't sure how our friends in Belgaum would react though. So when I wrote to them about what Nama Tai said, they immediately sent me a letter authorising me to carry out their correspondence. At that time we at Helpers too had a long waiting list. Still we sort of became a nodal agency for other disabled organisations, spending on trips to Mumbai, doing all their correspondence and supplied the benefits of the various schemes to Belgaum, Pandharpur, Ichalkaranji, Sangli and so on. But the Belgaum organisation, as always,



was tardy in sending us the required details, in fact, they didn't even respond to our phone calls. If we didn't send in their documents on time, they would lose the government grant worth at least seventy thousand rupees. And I'd given word to Nama Tai that I would help them. So we pitched in, cobbled up whatever information we could gather, and sent applications on their behalf. Chhaya Desai, Abhijit and I went to Belgaum. We also had to inquire about our own order for calipers.

We badly needed a caliper technician. Children who were operated upon had to be given calipers immediately or else their nerves contracted and all the effort would go down the drain. It had happened before. Therefore we contacted Mr Samudre from the Belgaum organisation to train our children. Samudre was resigning from there in order to go to the Gulf. But he would have some time between his resignation and getting his visa. So he was glad to come to Kolhapur to fit calipers for our children. I forwarded Samudre's proposal to our committee and we decided, with his help, to start making calipers at Bhaijaan's flat which was now our vocational training center. Within eight days, Janvadkar Kaka and Dr Mohanrao Gune procured machinery worth Rs 50,000 and training began. We took on Arun Lokhande in order to train him to make calipers. He was only too happy to do so.

Rajendra Chauhan from Chikodi, a student of class eight, was the other trainee. One of his feet was almost rotting with a wound and his other leg ended at the knee. Dr Satvekar had been trying to treat his wound for a year. Finally I lost patience and told the doctor, "If the wound doesn't heal why don't you amputate his foot?"

But the good doctor said, "Naseema, I could easily amputate. But any body part that's gone is gone forever. Amputation should be our very last resort."

But after almost a year and a half when the wound didn't heal, Dr Satvekar had to accept defeat. "Take him to Mumbai and have his foot amputated," he said.

By now we had established a good rapport with the doctors at the All India Institute of Physical Medicine and Rehabilitation at Mumbai. They always gave our patients

priority over others and so Rajendra was taken in immediately. As usual, Uncle Haroon was there to help us. When Rajendra's father buried his son's amputated foot, he too grieved along with all of us. Rajendra stayed in Mumbai for several months and we bore all his expenses. When he finally returned to Kolhapur he was standing on two artificial legs. We immediately set about teaching him to make calipers. We put him on a stipend and he lived in Bhaijaan's flat in Atmaram Building. Soon he started cooking his own meals. Finally he was on his own and I was relieved.

Gradually, the training center expanded and Rajendra began earning more. But instead of sending money home, he began drinking heavily and chewing tobacco. I warned him several times but he didn't have the least desire to stop and finally I had little choice other than to send him back to his village. Before long he wrote me a letter asking me to forgive him. He wanted to open a kiosk to sell betel leaves and other little knickknacks and wanted financial help. His father stood guarantee for him and so I gave him a personal loan of part of the amount. When he repaid some of it, I gave him the rest. He'd been to see us recently and I should say that he seems to be doing rather well, if not very well.

The calipers and crutches that we needed were now being made in our own training center. We were not dependent on others and it cost less too. We were beginning to feel a bit relaxed, so it was a complete shock to get a letter from the organisation in Belgaum. It was from their President. I still have that letter with me. He wrote:

"You have snatched away our technician. You came here under the pretext of helping us prepare documents for our beneficiaries and did something that was damaging to us. I believe what you wanted, more than anything else, was to prove that you are spreading your work outside Maharashtra." (Belgaum was in Karnataka state).

I knew that the President was an alcoholic. He may have written this when he was drunk, but how could the Secretary, who was a very good friend, allow him to send it to me? Or did she too forget how I helped them to get land for their organisation? She had always maintained that her institution was as much mine as hers. In fact our two



organisations were like twin sisters, having been founded around the same time. Now she didn't even care to ask me about my response to this letter. Was this the same lady who often called us on the telephone and with whom we had such friendly chats? Now she even mailed a copy of the letter to Rajani. This was too much.

I replied. I enclosed copies of two letters—the one I had written to NASEOH with respect to the technician and the other I received from their own institution, authorising me to hold a NASEOH camp on their behalf. For days the letter haunted me and I felt as if someone was hammering me on my head. I can deal with the harshest physical tribulations, but was never very good with emotional shocks and betrayal of friendships. I was so traumatised that I was bedridden for a few days. Then one day, this “friend” said she was coming to Kolhapur.

I warned her, “Don't bother, I will not see you. You needn't come and bother Ma.” I mentioned this in particular because Ma usually went out of her way to look after my disabled friends. Despite her arthritis, she ran water for their baths, fed them and housed them. I often feel guilty when I think about this. And after what this woman did to me, I saw no reason to put Ma through all this trouble.

Later, when I received several awards for my work, the Belgaum institution wanted to felicitate me. But I didn't even reply to their letter. When my “friend” called me I told her, “Wasn't your letter felicitation enough? What gift do you have in mind for me now?”

I'm prepared to admit that they may have made a mistake. Don't we all make them when we are depressed or angry? But when you realise what you've done, you *apologise* and extend an invitation to re-establish the friendship. I was upset not so much because they wrote the letter but because they didn't bother to apologise even later. A few months down the line, the President, who wrote the letter, fell very ill. It took a lot from me, but I tried to set aside my grievances and went to meet him in the hospital with PD and Rajani. It was a gesture of respect for our earlier friendship. Our “friend” still comes here once in a while but our old emotional bond is strained.



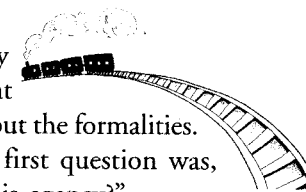
Our application to run a cooking gas agency was finally approved. Deshbhratar and I went to their head office in Mumbai to inquire about the formalities. They saw the letter of approval and their first question was, “How many lakhs did you spend to get this agency?”

We smiled and said, “Look, we only *receive* donations, never *give* donations!”

It took us the whole day to cut through the red tape. We had to have a showroom of a particular size in a residential area and the warehouse should be situated at some distance from there. We needed to have open space of a particular dimension around it on all sides. These were the instructions.

We returned to Kolhapur and started looking for a showroom. There were some spaces available in Rajarampuri and other places which were a bit cheap, but we would've found it difficult to manage the business so far away from our office. So we zeroed in on Tarabai Park. Fortunately, Balasaheb Patankar, who had inaugurated one of our sports meets, had some commercial shop spaces in Tarabai Park for sale. We negotiated a suitably low rate and bought two shop areas in the name of Helpers. It was a major step towards self-sustenance.

Now we had to look for a piece of land for the warehouse. We were out land hunting at least five or six times a week and then finally, after six months, we found a piece of land near Temblai that fulfilled all the gas agency rules. Furthermore, we had only a year to build or else our license would be cancelled. A sword hung over our heads, so we desperately juggled with our jobs and tried to finish building the warehouse. We requested the gas distribution company in Mumbai to inspect the land so that we could proceed. But there was no reply from them. What if someone else bought the land in the meanwhile? So we managed to catch hold of the gas agency representative stationed at Kolhapur (who, incidentally, was never available in his office) and made him visit our plot. So though we didn't get a formal okay from headquarters, we went ahead, signed the sale deed with the owner, put down our payment, paid up the stamp duty and informed the company that we were going ahead with the construction.



We were in the midst of these never-ending formalities when an officer from the Mumbai gas agency headquarters suddenly materialised in Kolhapur. PD and I took him to our plot. PD showed him our souvenir, *Bharari* which had a picture of a boy and a girl on the cover. The boy, who had no hands and feet was writing with a pen held in his mouth. The girl, on calipers, swung high on a swing. The officer snorted with a hrrrmph and shoved away the souvenir as if it was a cockroach!

"I've nothing to do with your work...welfare of disabled people and other things. Let's talk business," he said dryly.

PD and I gawked and gulped! Business? We certainly knew what *that* meant! We were stunned into silence by this blatant corruption. Since we couldn't come to a "business" agreement, the man rejected the land straight away! Now we had to cancel the sale deed and get back our money. Such a waste of time and effort as if we didn't have so much to do already. I suddenly remembered—Aziz was in India for his holidays. One day, an officer (I believe it was the same man) from the gas company in Mumbai came to approve of the showroom. I was busy, so I sent Aziz to meet him. In the course of conversation, the officer came to know that Aziz worked in Muscat and came to Kolhapur every three months. For the officer, the fact that Aziz worked in Muscat meant only one thing—the possibility of a hefty bribe! I should never have sent Aziz, it was a big mistake.

The warehouse had a history, blighted though it was. Briefly, what happened was this. As soon as we got a formal approval for the gas agency, we applied for land in the industrial area of Shirali, which was under the MIDC (Maharashtra Industrial Development Corporation) to build our warehouse. With the intention of starting a vocational training center in the same premises in future, we applied for twenty thousand square feet of land. But we knew that the entire procedure would take quite long and we didn't want to lose the gas agency for want of a warehouse. That's why we went for the private piece of land. The MIDC application was still pending though we had some more documentation to do.

Now, when our private land was declared "unsuitable" by the good officer from the gas company, I rushed to Mumbai. We were about to visit the MIDC office, so we

called to find out if Mr Pathan, the officer in charge, would be in. His secretary told us, "Mr Pathan's on his way to Delhi this morning. But if you come early I'll arrange for you to meet him."

As always, we stayed with Rehana in Mumbai. That morning, just as we were preparing to rush off to the MIDC, we discovered, to our utmost horror, that the lift was out of order! We had to clamber down five flights of stairs, me on my wheelchair! A perfectly ghastly prospect! The landings were so narrow that my wheelchair had to be hoisted right up at the corners. But Rehana, her daughters and my assistant, Arun Lokhande, all drenched in perspiration, puffed and panted but somehow managed to haul me all the way down. I was taut with tension—what if one of them got hurt because of my wheelchair? Also I hoped we wouldn't miss Mr Pathan. Bhaisaab, as usual, had hired a taxi for himself and put his own car at my disposal, so we reached the MIDC office bang on time. We had yet more steps to negotiate—steps, steps, steps, a disabled person's nightmare!

Mr Pathan's PA ushered us into his cabin. He scanned through our documents—reports and photographs—and picked up the phone. He dialled the MIDC office in Kolhapur. In the meantime he ordered some tea. We heard him, loud and clear, remonstrating the officer, "Aren't you ashamed to make a lady on a wheelchair run all the way to Mumbai? Why haven't you sent her file to our Mumbai office? I'm leaving for Delhi today. By the time I return, I *must* have that file on my desk!"

We went weak with gratitude. He didn't even know who we were. People like him are always surprising us with their kindness and are responsible for the very survival of organisations like ours. I thanked him profusely but he said, "It is I who should be saying sorry to you for the delay. Just relax and go back to Kolhapur. It's good karma to help organisations like yours. Moreover, I'm just doing my duty."

"When should we come to get the approval letter?" we asked.

"Oh no, you don't need to come. We'll despatch it to Kolhapur," he assured us. And sure enough, shortly, we were able to take possession of the land for the warehouse.



The bhoomipoojan (a ritual worship of the land which augurs auspiciousness) was done by Balasaheb Janwadkar, Babu Kaka's close friend. All my disabled friends and I, we scooped up a bit of the soil in our hands. This was *our* land!

My trips to Mumbai were never-ending. Now I had to go again to get the building plan approved. Further, I had to appear as if I knew how to run a business, something that tasted like bitter gourd to me! I must've sounded very knowledgeable because the plan was approved. Somehow, I'd never thought of the gas agency as a "business," but rather as something that would provide us with a permanent means of income. Once we repaid the loans, the income from this would be sufficient to run the hostel, we thought.

The warehouse was constructed. Now we had to get a license for stocking explosives (another bit of paper). The paperwork went on and on and so did our trips to Mumbai. This time we had to get a concerned officer from Mumbai down to Kolhapur to show him the building. We went to the office. One of our "well-wisher" friends in Mumbai, who helped us negotiate all this cumbersome government red tape, came to our rescue. Till date, I've no idea what he told the officer, but our work was done without physically taking the man to Kolhapur. By now, I was completely exhausted, though we had been granted the license. All this "business" affair tired me no end unlike the actual work I did with disabled people night and day.

Then there was the matter of the contract which had to be signed with the gas company before March 1993. Once again I was headed for Mumbai. I always travelled by train.

The red tape was a mind-boggling mountain that we disabled people found very hard to cope with! While the contract documents were drawn up in Mumbai, the signatures would be from Pune, which was the divisional office. But before that we had to get a letter from the District Collector in Kolhapur. Now it was again a race against time especially since we couldn't get seats on any train. So we hired a taxi to Kolhapur. On the way, we had to wait near Karad because a tanker had caught fire on the road. As we sat in the car and waited, I recalled our own accident while travelling in the Sahyadri Express.

Here's the story. Anutai Bhagwat had put together a slide show about Helpers. To do this, she spent her own money on a projector and invited us to Pune for the first screening. After the show, she wanted to gift the projector to us. A well-made slide show was essential for us to be able to reach out to the public with whom we had little time to maintain a proper rapport. This rapport was as important as the actual work we did. Anutai noticed that even the people of Kolhapur knew nothing about an institution that was doing valuable work, right there, in their own city. The well-known photographer, Anil Velhal was instrumental in creating the slides. Anil, first a friend and then a volunteer, was someone we all counted on.

I could call on Anil any time of the day especially when I felt incompetent about getting something done! It was always Anil to the rescue whether I was going to Mumbai or Delhi or a sports meeting. If I was stuck at the municipal office practically the whole day, my work nowhere near getting done, Anil would rush there and take a crack at it. He insisted that I call him "Anil" not "Mr Anil."

So Anil and his brother, Pramod, made all the slides while Anutai drafted an impressive commentary to go with the presentation. The title of the show was *Amhi Pudhech Jau—We Shall Go Nowhere but Ahead*. The first show was organised in Pune where we were also to be gifted with the projector. I was very keen that PD and Rajani should come for the function to Pune. Rajani and Vishranti joined us. Since, as disabled people, we got rail concessions, we decided on getting first class tickets on the Koyana Express. Finally I could have a leisurely chat with PD on the train. Work kept us all so busy that we could rarely have personal conversations.

The slide show was a thundering success, beyond our wildest expectations. We now had a perfect tool to reach out to people. Anutai's commentary was touching:

"We shall cross all hurdles and go nowhere but ahead, we shall touch the moon in the sky, that's our future. Misery knows no caste or community, misery knows no religion, no boundary. This shackle of misery when removed gives new movement to stumbling feet."

After the show we boarded the Sahyadri Express. We were four of us in the first class compartment. A smart young boy,



Suresh Gurav, my colleague at the Central Excise department, came to see us off. He placed the projector on a small stool.

"Be careful," I said, "it may fall."

"Don't worry, it won't," he assured me.

"Let's keep it *under* the stool, why take chances?" I insisted. I have a bad habit of insisting and getting things done my way.

We pulled out of the station, and got chatting. Rajani, PD and I talked and talked and when I looked at the watch, finally, it was 2.30 in the morning! We had to get some sleep since we had to report to work the next morning. We were just drifting off when suddenly there was a big THUD. We sat up, alert. The compartment was full of smoke. Was it an earthquake, dacoity or fire? The train jolted and lurched and Rajani and I held on to our berths for life. The coach seemed to slant and the train had come to a standstill. PD tried to open the door but we stopped him. It was only when we heard sounds of what we assumed was a crowd outside that we opened the door. It was then that we realised what had happened. What we took for smoke was dust. The train had derailed and split into eleven parts! About seven coaches were derailed. A big iron rod lay in front of the door.

Seeing the extent of the disaster, we were surprised that our little brigade survived, unhurt. The doctors rushed in because we were disabled. But, if truth be told, we were more worried about the projector! It was still intact, a miracle, nothing less. It was 3 am. A good thing that the derailment happened at night when everyone was still asleep. Had it taken place during the day, there would have been panic and people would have tried to jump out only to meet with death.

It was then that Anutai's packed meal of rotis and chutney came to our rescue. Food never tasted so good. We'd told her that we wouldn't need any since we'd reach Kolhapur in the morning, but she insisted and just to please her we took it. But now, by the time another train was arranged for, it was 11 am and we were hungry and boy, weren't we glad to have that food!

But our troubles were far from over. The new train was on a track opposite ours but there was no platform on which to descend—we were still mid-track. Shifting Rajani and me

from one coach to another was not an easy job. Moreover, we didn't have our experienced helpers on hand. But as always, society came forward with its precious help. Passengers and railway officers managed it all ever so gently that we didn't feel awkward even for a moment!

Deshbhratar received us at Kolhapur station. Knowing that our folks would be very worried about us, he'd merely told them that the train was late, keeping mum about the accident. We reached home at noon, had our baths, ate something and quietly went off to sleep. There was no question of attending work.

Now, as I sat in the cab, watching the burning tanker, I wondered why Karad was so jinxed. Once a mini bus in which Rajani and PD were travelling turned turtle right at this very spot! And again, fortunately, they were not hurt.

But unlike after the train accident, I couldn't rest at home this time. We had to get the District Collector's okay and then rush off to Pune to get the signatures. Uncle Haroon and Vishranti came with us.

We drove directly to Deshbhratar's house, picked up Neeta and went to the Collector's office. I requested that our work be attended to urgently (our papers were not ready!) since we had to proceed to Pune. Then I went home and had time just enough for a bath.

Ma said, "Eat your lunch."

"Could you please pack it for me?" I asked her. "I'll eat in the taxi."

It was the last day and we had to reach Pune by 3 pm and sign the contract. Neeta and I rushed off and reached Pune...just on time. I heaved a huge sigh of relief. The papers were signed. It was midnight before we reached Kolhapur. The cooking gas agency was on and we could begin bookings.

Getting a cooking gas connection in those days was a daunting task and one that forced many people to use other cooking fuels like kerosene. I myself was not able to book for a gas connection so far. Every time I made inquiries I was told that the booking was not open and I should check again. With that kind of "gas connection" history, I was determined now to free the common person from standing in long queues for kerosene and kept bookings open for all. We had permission



to operate in the area that came under the jurisdiction of the Municipal Corporation and residents from any corner of Kolhapur could register with us. So we were in a position to both “earn and serve” by supplying cooking gas to the common person’s kitchen.

Luck was in my favour. There was a wedding in the family and I insisted that all my folks should attend it. I am not fond of dressing up and participating in marriage functions. Moreover, I had to be in Kolhapur when we were just about to start the agency. Neeta and Vishranti would look after me. So every one (thankfully) left and we had the unrestricted use of my house for eight days, a crucial eight days. Fifteen to twenty workers of Helpers were there round the clock. Our dining table became our office table.

It was perhaps for the first time in the history of Kolhapur that bookings for gas were open for all. On the very first day we had more than five thousand people. We found it difficult to give receipts to everyone in one day so we kept their papers and gave them a coupon for collection of receipts. We worked madly, taking turns day and night, to ready the receipts before the date.

We could barely accommodate the swelling crowds in our showroom, so we placed a table outside, near the road. It was a table made especially for me so that I could work sitting on the wheelchair. It was the month of May and terribly hot and sometimes we got some pre-monsoon showers. But we used an umbrella and continued our work. Once there was a row about breaking queues and in the course of the fight, someone went thump on my favourite table and it collapsed! We installed a loud speaker so that we could communicate with the public and maintain peace. Sometimes we had to call the police to control the mob. Then, as always in such cases, touts appeared on the scene, bringing with them piles of ration cards (considered to be bona fide ID) and other papers. But we had opted for free and open registration, so it was with great delight that I tore up the papers that the touts thrust at us.

Once, a posse of policemen had come to control the crowd. In the melee that ensued, one of our volunteers who was fixing the loudspeaker got squarely hit. I rushed in where fools fear

to tread, and then retreated in haste when I felt that my wheelchair was about to meet the same fate as my table! We stopped all registration. Instead we brought a tin and carved a hole on its head.

“No registrations till you contribute towards fixing our broken table!” we announced.

Money started dropping into the tin. When we counted the amount at night, we discovered that we had enough money not only to fix the old table, but also to acquire a new small Godrej table. We couldn’t have afforded it, so it was just as well. Don’t I always say, “Whatever happens, happens for our good?” We worked day and night. To save time on cooking, we had bread and eggs and pav bhaji (bread and curry).

The gas agency was now fully functional. We all took as much leave from work as we could by turns and kept the showroom open full time. We were trying hard to be good business people but we weren’t getting far for many reasons. We were prompt in our delivery of gas connections. Now, there were many who had registered with other dealers who were tardy in supplying connections. They began complaining to those dealers. So they transferred that list to us and we began to service them. Some of them had registered as long as ten years ago and they were given “temporary” connections. So they’d already acquired their cooking stoves. Now the dealer’s profit comes from selling the stoves. The deposits and the price of the actual gas go to the gas company. That left dealers with a paltry commission from actual sales. Thanks to those inefficient dealers, we now ended up servicing those clients who’d already got their stoves. That meant no profit from selling stoves and we were spending far too much on petrol, salaries, rent, telephone, electricity and water from our commission. We made little money. Not only couldn’t we repay our loan, but we ended up paying interest on it. We’d worked so hard to get the gas agency in order to be self-sufficient but were not making much headway.

So we told our customers, “Look, we’re helping you to regularise your connections though you’ve already bought your stoves. So please give us donations.” Some gave readily, but some were tight-fisted. We had to get on with our lives, our



jobs, so we handed over the management of the agency to our staff. They seemed to be doing their jobs well.

It was now time for me to turn my attention to our hostel project at Uchgaon. I took stock of the situation (I was supposed to be a businesswoman!)—by the time we repaid our loans for the gas agency the hostel should be ready, then the income from the agency could be used to run the hostel.

Architect Pramod Beri, a donor and well-wisher, drew up a plan. We had several site meetings with him and he listened to us very carefully. He had to be completely aware of our special needs. He'd already been to Kirkee in Pune to see the building for disabled soldiers and researched on similar buildings abroad. Soon a draft was ready. The land was so uneven that we wondered how suitable it would be for disabled people. But Beri's sketch was so beautiful that we were excited. A dream about to come true! Our own home without a *single step*! We wouldn't need people to lift and carry us!

Our excitement was short-lived though because the costs were gargantuan. But Beri said, "Let's begin work, funds will follow." He put us in touch with donors. Rehana's husband managed to get us some funds from Mumbai. Udaysinharao Gaikwad, MLA gave us Rs 5,00,000 from the Chief Minister's fund. My relatives put together some money for one room. And I drew some money from my general provident fund to fill the gaps.

Rajani and PD did the ritual bhoomipoojan on our plot. We wanted to begin with the fencing of the land. When we did the survey we discovered two huts, one at the boundary and the other right in the middle of the plot. We were not so concerned with the boundary one (God had given us two acres of land, a few square feet would hardly matter) but what about the one in the middle? It seemed unfair to oust someone out of his home and render him homeless while we built our own. Fortunately, Annappa Chavan, the former sarpanch of Uchgaon and Ganesh Kale, the current sarpanch gave the man a small plot of land outside our boundary where he could build his hut. We took care of his expenses. We invited the District Collector, Ajitkumar Jain to bless the turning of the soil for our new borewell.



But things were not to stay peaceful for long. Some people who owned land around that area began to raise objections about the "free" allotment of land to us. They belonged to a community of backward nomadic tribes who believed that the government should have given them free land too. They gheraoed our land and stopped all work with the result that the workmen couldn't build our compound wall. I had little option but to take complete charge. I took leave from work and sat in the scorching sun with an umbrella over my head till the compound wall was finished. But the road leading to our land was so treacherously full of pits that I feared that I would rupture my spinal chord (and my wheelchair) by the time the wall was over.

Balasaheb Ingrole, another of our well-wishers, put us on to the Kalpavriksha Tubewell Company from Jaisingpur who would dig our borewell free of cost. A date was fixed to begin the boring. We called for a water diviner who picked out a spot bang in the middle of the plot. The next day, the District Collector and Anutai would arrive to unveil the signboard for the hostel and digging would begin in earnest. But at 5.30 that evening, Annappa Chavan came to see me. He had an air of urgency about him.

He said, "Do you know that in the area around Uchgaon, there have been at least sixteen unsuccessful attempts to dig a borewell? Why are you going to all this trouble? Only to waste your time and money?"

What's this! Everything was ready for the borewell ceremony tomorrow and we were expecting important guests. I had to act fast. I called Dastagir Pathan who worked in the Zilla Parishad and who was also a member of our Administrative Committee.

I said, "Please get a man who has a gadget to detect the underground flow of water. Let's take him to Uchgaon now!"

The District Collector's imminent visit the next day must've put wheels on the technician's feet, because he arrived with his gadget before sunset! It was getting dark so we rushed to Uchgaon. But the last rays of the sun were rays of hope for us. Before long, the technician located a spot on the western corner of the plot.

Anutai supervised the digging the next day. The Collector's presence had more than one use—we spoke to





the people who'd gheraoed us and sent them back. That evening, as we waited with bated breath, the water....gushed out of the well in one long spout! Water, precious water! Our land was not arid after all! The beautiful setting sun and the water that sparkled in its last rays were witnesses to our boundless joy.

What we needed more than anything else was water for the construction and now we had that. We needed to install an electric motor and pull up the water in a hurry. The digging carried on through the night which was cold and windy. We gave food and blankets to the workmen.

Before the installation of the electric pump (we now had a hand pump), Deshbhratar and I had to take a water tanker to Uchgaon at least four times a day. Most often, the tanker was not available during the day, so we had to go at odd hours during the night with the tanker following our rickshaw. What a strange experience for a paraplegic!

Though Deshbhratar helped me whenever he could, I had to go alone to the land a lot of the times. The rickshaw drivers were friendly and helpful but we had to pay extra charges because Uchgaon was quite out of the way. I realised then that Helpers desperately needed its own vehicle. I'd arranged for a couple of chairs at the site. Sitting for such long hours made my feet swell so I placed them on a chair in front of me and I felt miles better. Sometimes, all I had to do was sit like this for hours and it was at times like this that I wished I could write down my experiences on a piece of paper. But anyone who has supervised construction would know that this is a useless aspiration. I was busy, busy, busy!

So now we had water, but of what use would it be if it stayed underground? Electricity—that was our next requirement. We (past masters of applications!) applied for electricity. HD Patil and his colleagues at the Maharashtra State Electricity Board gave our application an early push and in twelve days, the poles were up. Now there was water *and* electricity. What we needed was a motor to pump the water out. As always, all our little efforts were celebrated with a ceremony. So HD Patil came along to start the inaugural motor. The water rose up in a thick whoosh. I couldn't help thinking, "Oh, so this is what they meant when they said

that there was no water around Uchgaon? Sixteen attempts and no water! Well, we beat them to it, didn't we?"

Actually, I was quite moved and I think Anant Dixit, the Editor of *Sakal*, noticed me quietly. He was always there to share our triumphs and travails. It must have been quite a sight—water flowing out of a borewell in the hot sun and a bunch of disabled people thrilled beyond words! He must've been rather overwhelmed, because in his speech he said that I was the Mother Teresa of Kolhapur! I remembered then my plans to meet Mother Teresa.

I'd been wanting to meet Mother Teresa for a long time. Just a few minutes with her and I would consider myself blessed. We had our bookings—Kolhapur-Nagpur-Kolkata and back to Kolhapur. Bimalendu Chakraborty from Kolkata had made arrangements for our stay. I'd met him at one of our sports gatherings. A very nice fellow, as sweet as rasagullas! He'd been inviting us for a long time. It was the Diwali vacations. The office was buzzing with activity because it was bonus time. I was in the thick of preparing documents when I discovered some miscalculations in one of the bills. It was getting late but I had to rectify it. I decided that I would double check the next morning and then issue a cheque. I must leave behind a clean desk before I leave for Kolkata.

I usually wore some gold ornaments—a chain, rings and bangles—but only to please Ma. When I come home, I remove everything, wrap them in a handkerchief and stuff them in my handbag. My routine was to wear all these ornaments after my bath. As I sit in front of the mirror, getting ready, I'm hardly aware of what I'm wearing or that someone is talking to me. My mind is all abuzz with my engagement diary and office work. That particular day, just two days before leaving for Kolkata, I was more distracted than on other days because I had so much work to complete. Ma had laid out some of my things for me to wear after my bath. I was in a hurry and thinking of everything but the gold ornaments. I pulled out my handkerchief but forgot to wear the ornaments. It was only when Neeta scolded me saying, "Didi, why no jewelry? Go on, put them on, you look so bare," and when I felt around my neck and ears, that I realised I hadn't worn them. I checked my bag frantically. Nothing. I decided that I would take the same



route home in case the jewels had fallen on the ground. The queue for the kerosene wound along the road and almost reached our house. The road was brand new and pitless thanks to Rajendra Khanvilkar—the Councillor—so there were no holes into which the jewels could've fallen. It was a clear day and the jewellery would have shone in the sun. I searched at home, under my bed, everywhere. Nothing. Oh God, what will Ma and Aziz say? These were gifts from them. For the nth time I wished that they hadn't spent all this money on me, I wished I'd bought them myself, I wouldn't have felt so wretched.

By now I was completely crestfallen. I returned to the office, issued the bonus cheque and sent two telegrams to Nagpur and Calcutta—"Visit cancelled."

I had everyone's sympathy, but I couldn't pardon myself for being so careless. How could I enjoy myself in Kolkata after what happened? Thus, because of my carelessness, I couldn't meet Mother Teresa. I've never been able to go there after that.

Despite my carelessness Ma and Aziz got me more jewellery. But do I really *need* them? I wore them just so as not to displease them. Don't they pamper me to death already?

But I digress and must perforce get back to the story of how we built up our institution, step by step. Now that we'd built the compound wall and dug a borewell, we had to have yet another ceremony (we loved ceremonies)—laying the foundation stone. But who would be the right person to do it? Bhaisaab suggested that it should be one of our disabled members. Bandu Harale was the unanimous choice. Bandu was so badly disabled that his mother had to carry him when he came to visit us for the first time.

Dr Satvekar operated on him and with sustained treatment he was now walking on crutches.

The event was a happy one. Mr Nigam of Messrs Nigam Sanitary Constructions (whose tender we'd approved) offered all arrangements including tea and snacks. We had the blessings of all those who'd been associated with us over many years—Aai Saheb, the Maharani of Kagal, our Founder Member, Vijayadevi Ghatge, Retd Justice Subhashchandra Desai, Deputy Superintendent of Police, Bhagvantrao More, industrialist Shivajirao Desai, our donor from Mumbai, Madhavprasad

Goenka, Nana Beri, Puntambekar, Rehana, Khan Saheb, Uncle Haroon, Anutai, Kamlati and so on.

The day before the laying of the foundation stone, we had dinner at "Nasheman," my home. We invited some of our volunteers, donors and well-wishers. I desperately wanted Bhaisaab to meet them and invited him to come from Mumbai. All these years, Rehana and he have been our strongest pillars of support. Bhaisaab was to arrive in the afternoon but he turned up around midnight when all the guests had left. By the time I left for Uchgaon very early next morning he wasn't yet up. I noticed how drawn and tired he looked. Desai Kaka then told me, "You see, Bhaisaab was coming to Kolhapur from Karvar. He had to cross the river for some distance in a small boat. The boat capsized and you know he can't swim. He was saved by some people and had a narrow escape!" The fact is that Bhaisaab rarely comes to Kolhapur but he agreed just for me. And so without wasting any time to see a doctor, he rushed home in order to make it in time for the dinner. Now I knew why his shoes and socks were soaked!

Kamalatai Sovani was a ninety-year old freedom fighter. She donated Rs 55,000 towards our plumbing expenses and water supply at Uchgaon. She'd sold her jewellery for this but swore us to silence. Kamalatai has since passed away but we have her blessings, I'm sure. Each of the guests who came for the foundation stone laying ceremony planted a tree. I still remember Kamalatai's words, "Naseema, these trees *must* survive. Appoint someone to water them. If you have a problem I'll pay him." So Prakash Kale, who lived in the nearby slum in Uchgaon, and who was employed as our watchman, was to take care of the plants.

What a moment of joy as we gathered together on our hard-won land! The presence of our elders, who spoke so eloquently, and who stood by us all these years, was overwhelming. At that moment, I allowed myself to forget all my bitter experiences. Normally I like to share my joy with others but keep my sorrows to myself. But when I decided to write this book, I felt that it should be a truthful account of my life, however bitter and sorrowful some parts of it may be. There was no point in selecting just the happy experiences. It was never my wish to criticise or hurt anyone,

but the truth needed to be told at any cost because it may be easier for those who plan to undertake such a challenge as I did. So what you get is nothing but the absolute truth.

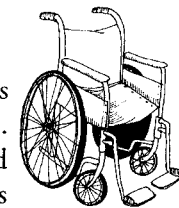
But wait, I must take you back two days before the function and to our state of frenzy not unlike the organisers of a family wedding! We were nervous as hell. Out-station guests were to arrive the day before. Sharfuddin Kapdi, owner of Mera Hotel, would host them at a discounted tariff. Everyone was doing his or her job. And suddenly, in the middle of all this, we got a phone call. It had a history.

For the past four or five years we were trying to get a grant from the central government for artificial devices and appliances. It so happened that our documents were taken to Delhi this year by our Member of Parliament. There was to be a routine inspection by central government officers before the grant was sanctioned. One such officer had come as far as Pune. Since I was the President of Helpers, he called to speak to me. I was to go to Pune with my papers. I was also supposed to make a first class train reservation for him to go to some remote destination. But what a time for the call to come! There was no time to have a meeting in order to take a decision. I contacted some members of the Executive Committee. We had little choice but to follow the instructions we received on the phone with the hope of getting a permanent and substantial grant. We were desperately short of time, so it was decided that Deshbhratar and I should take a taxi to Pune and the rest of the committee members would look after the foundation stone function. I was terribly tired and the journey looked forbidding, so I decided to try one last shot by inviting the officer to our function. We assured him that we'd made his train reservation. He said he had no time. What could I possibly do? I wouldn't be there to welcome our out-station guests. Anyhow, we took a taxi (and of course, the officer's train ticket!) to Pune. At Pune, we went straight to the waiting room at the railway station and washed up. Then we went to the hotel where the officer was staying. We were depressed and exhausted but we tried to be pleasant. The officer spoke in Hindi and had a pleasing air about him. He looked through all our papers and finally stamps were affixed and

we signed! What a blessing that he didn't keep us hanging around like most government officers! That was the most fortunate part.

The grant was for three years. Little did we know then that it would be so much trouble. We got the cheque at the end of March or in April and we had to furnish a utilisation certificate for the entire amount by March the next year. We had to deal with mountains of paperwork—medical examinations, calipers according to requirement, materials from Kanpur and many other things. Though the time for all this was too short, we had to send in our accounts on time. And worst of all, it was mandatory to invite some government officer when it was time to distribute these devices and appliances. (Once, after we'd planned everything, including printed invitations for the event, the materials didn't arrive from Kanpur. So we distributed appliances made in our own training centre.) The government grant never exceeded Rs 40,000 but Helpers used to give away materials worth three lakhs. On top of all this, the Social Welfare Department happily forwarded applications received by them to us and made it obligatory for us to use *our* grant for them. More than half our grant was spent thus. We stopped applying.

I'd mentioned earlier that we were using Bhaijaan's flat in Atmaram building to make our appliances. The machines made a horrific noise and disturbed the people living upstairs especially in the afternoons when they took a siesta. So for some days we stopped working in the afternoons; still they complained. Bhaijaan charged us a nominal rent of one thousand rupees a month. But since he was renting out his property, he had to pay extra house tax. On top of that, he gave us a donation of at least Rs 5,000 a year. This way he returned nearly half the amount he received as rent. Now he had to pay the increased house tax as well. We couldn't possibly justify this. So I put the matter before the committee and we decided that as long as we used his flat, Helpers would pay his house tax too.



It so happened that when we were looking around for a suitable place for the gas agency warehouse, we spotted a community cultural hall at Kadamvadi (I believe it was used primarily for gambling and drinking). Shards of glass lay all around and the windowpanes were broken. Hmm...with a little sprucing up, this place wouldn't be bad for our training centre, I thought. PD, Rajani, Deshbhratar, Abhijit, Chhaya and Irshad—they all saw the place. This was in 1995. Of course, we'd have to get it renovated and made suitable for a workshop, so we called on Sandeep Ankle, the architect who designed our gas agency showroom. Special attention had to be given to toilets and bathrooms to make them disabled friendly. The Municipality (to whom the hall belonged) quoted Rs 1,700 as rent. Despite all our bargaining they refused to reduce it. We took it anyway.

Now that we had the space we needed the expertise. We made contact with the Vocational Rehabilitation Centre run by the central government in Mumbai. I went there on a faculty hunt for our centre. Mr Narasimhan and his colleague, Mr Lavangare, agreed to conduct different vocational courses of three, six and eleven months. So we divided the disabled students into groups. During the first year we had courses for repair of electrical gadgets, screen-printing, bicycle repair and making rubber stamps. We invited an officer from the gas company to inaugurate these classes. What a relief it was to have our own premises! Our machines could make all the noise they wanted and no one's siesta would be disturbed!

At first we admitted only male trainees. Mrs Gadkari was appointed as cook and her husband Haroon Gadkari, who had an artificial leg, was appointed as watchman. But soon the girls wanted to get admitted too. Mukta, Surekha and Kanchan were at the forefront of this demand. The Executive Committee, perhaps a little conservative, wanted to avoid the complications of young men and women living together, the training centre being a residential place. Making it a residential centre would facilitate rural trainees to join which they couldn't if they had to commute from their villages everyday.

But Rajani and I spoke about it, "How long would disabled women be confined to their homes? There seems to be always a reason for them to be that way but it's time we

opened our minds *and* our doors. We'll tackle the problems if and when they arise but these girls should not be denied an opportunity to be trained along with the boys." We convinced the Committee. Mukta, Surekha and Kanchan danced with joy.

Mukta had no father and her leg was polio-affected. She walked with crutches. Meanwhile, the number of residents shot up from about twenty to forty. Pregnant Mrs Gadkari couldn't manage alone so Mukta took charge, ably assisted by Surekha and Kanchan. The male trainees weren't let off the hook as far as kitchen chores were concerned. They woke up early and made chappatis. Sweeping and swabbing the floors, cleaning the bathrooms and courtyard, gardening—the trainees did everything. What was unfolding in front of my eyes was a rehearsal of how our hostel would be in Uchgaon.

Around that time I met a pretty young girl, a twenty-four year old paraplegic, Sadori Chandwani. She was brought by her brother and had bedsores. Five years ago, she was engaged to be married but met with a cruel accident. Like all young girls, the local Temblai fair, with all its rides, beckoned her. One of her dreams was to ride on a giant wheel. So she bought herself a ticket and sat in one of the cradles. It turned out to be a deadly cradle, because just as the wheel reached its highest point, it snapped and fell all the way down. She broke her spine and became a paraplegic like me. The engagement was called off and there were to be no dreams of a happy married life. Her disability too was pretty extreme. I could well imagine what she was going through. Convinced that she would start walking and stubborn by nature, she wouldn't even sit in a wheelchair. I realised that she nurtured hopes that some big doctor in Mumbai would cure her completely. It was then that I had to tell her to face the truth. But still she needed treatment so I took her myself to the biggest hospital in Haji Ali, Mumbai.

On that trip I took the opportunity to finish some work in Mumbai concerning our application for the Uchgaon hostel. I got Sadori admitted. I also took the opportunity to visit the Paraplegic Foundation in Sion to see the special arrangements they'd made for their patients. I made it a point to see as

many institutions as possible to study what we would need for our hostel.

At the Foundation we were informed that there was to be a sports meet for paraplegic people at Vashi. I was delighted especially because this was an ideal opportunity to tell the depressed Sadori that she was not alone, there were hundreds like her who did well in education, sports, the arts and so on, living happily and with self-respect. I urged her to come. Those days I hardly had any time to keep in touch with sports occupied as I was with institution building and my job. So I wouldn't participate personally of course, but it would be lovely to meet my old friends.

They were delighted to see me on the grounds out of the blue. Sadori refused to participate though everyone urged her to, so they turned to me and though I pleaded that I was so out of touch, they insisted. After all these years I was once again on the play field and the old bug bit me. I won five first prizes in cash. Lovely, that was my taxi fare from Haji Ali to Vashi! I spent the rest of the money celebrating with Rehana's children the next day.

But the real purpose of attending the sports meet lay somewhere else. I suppose fate had decreed that I should meet a living miracle on the sports ground. The name of that miracle was Narendra. He was tall and majestic like a mountain. But his size belied his child-like smile and he had an unbelievable joie de vivre. But could anyone guess what was going on in that mind of his? Could it be that he was like a dormant volcano ready to erupt? Physically, he was very disabled—one hand, hearing aids and wheelchair bound. But there he was on the playground, spinning around in his wheelchair, wielding the ball with amazing dexterity, laughing and talking. I was stunned—should I be happy about his fortitude or sorry that God had chosen someone like him to be so badly disabled? The pang in my heart was mitigated by the therapeutic value of seeing him. And then something special happened in me—a profound shift of attitude. Narendra wiped out any last vestiges of self-pity I had about my own disability. I was physically rehabilitated already, now he helped me to get on the path of my mental and spiritual rehabilitation.

I was hard pressed for time with all the work I had to complete. Hurriedly, I congratulated Narendra and spoke a few words on the mike just to respect the organiser's wishes. I extended an invitation to the Cheshire Home, Andheri, and to the Paraplegic Foundation to send their throwball teams to Kolhapur where we were going to organise a sports meet on World Disabled Day. Mentally I made a note to start coaching our teams to play throwball on wheelchairs. It would be entertaining and good exercise as well.

When I reached Kolhapur I so much wanted to write to Narendra but I was overworked and slept hardly for three hours a night. But he did come to Kolhapur in March 1994 with the Cheshire Home team. I was President of Helpers and also in charge of the sports meet, so I couldn't spend much time with the teams. Renuka Bondre, who had a private hostel, housed the players. She supervised everything herself, from meals to beds. We arranged a special bus for a sight seeing trip. At that point I said goodbye to all my pending work so that I could go with them in the bus.

I noticed that most of the wheelchairs the Cheshire Home team used were not only broken but totally useless. One of the young men decided to tell me Narendra's story. Later, when there was a lull on the field, I began to cry. I couldn't stop, the tears flowing down my cheeks. PD had told me never to make a public display of my emotions and now everyone saw me cry. Between my racking sobs I thought, "How could I possibly believe that I could remove any misery from the world despite all my efforts? It was impossible! Suffering is life."

It so happened that a certain gentleman was present from a well-known organisation. I pointed out the eight rickety and worn out wheelchairs and asked him whether he would consider donating eight new wheelchairs. He agreed and so I requested the Spanish sister from the Cheshire Home (she had re-named herself "Pushpa" which was easy to pronounce and also had the same meaning as her original name) to send him the necessary documents, applications and photographs. Now I felt a little easier.

Let me now tell you Narendra's story. Once, in 1986, when he was away from his hometown, he was administered glycerol by mistake. The glycerol sent him into a coma for

about four months. When he came out of it, villainous destiny had wiped out his memory. (Later it came to be known that his driver had run away with all his belongings—papers, suitcase and cash, thinking that he would die). There were no relatives either who came for him. So in the hospital records he was entered as “Unknown Person.” His legs had collapsed, he couldn’t speak or hear and his vision was impaired. He was treated in various hospitals and with sheer willpower he managed to negotiate a wheelchair with one hand. He learnt Hindi and English and composed poems which he wrote down with a pen fitted on to his left hand with an appliance. He could hear with hearing aids. With his tremendous willpower he could now brush his teeth, shave, have a bath and was great in sports. Narendra rose like a phoenix from the ashes.

In 1992, when the hospital couldn’t do anything more for him, he moved to the Cheshire Home, Andheri in Mumbai. The place had all the facilities he needed but he was restless. He had such a strong spirit of exploration that those who knew him thought that he must’ve been a doctor or researcher before he lost his memory. One thing he hated more than anything else was being an object of pity. He wanted to be independent but had no opportunity to be so. It was during this phase of his life when he came for our sports meet to Kolhapur. He sang a song for our cultural evening—“*ghungru ki tarah bajta raha hun*” (I keep making sounds like an anklet bell). At the train station, just as he was leaving, he recited a poem for me which went deep into my heart. Narendra made an unforgettable impression on me. I’ve been looking for that poem in my files to put it into this book but can’t find it.

Now he was back at the Cheshire Home. The wheelchairs never did reach those young men. I felt miserable since I’d given my word to those eight fellow brothers. I myself had a fancy imported wheelchair that Aziz gave me that cost Rs 30,000. It was time for me to pass on my good fortune. I took a loan of Rs 5,500 that would cover the cost of one Indian wheelchair. I expressed my anguish to Renuka Bondre and she sent us a donation for one more wheelchair. I placed an order for two wheelchairs from Kanpur. Now I had to arrange for the other six chairs.

We were very short of funds which delayed the construction of the hostel. I was busy shuttling to Mumbai for donations and with Desai Kaka’s help managed to get some. But we were nowhere near raising our required amount. Finally we had no choice but to take interest-free loans from well-wishers. Ma and Bhaisaab didn’t think this was a wise idea, but we went ahead anyway, hoping that we would be able to raise the money in the near future. If we stopped construction it would be next to impossible to start all over again. All these thoughts kept churning in my mind as I went to Mumbai.

During one of my trips to Mumbai I met an old classmate of mine, Suneeta Anavkar after a gap of nearly twenty-five years. She was impressed with our work and helped me whenever she could. She wanted to introduce me to a big donor and asked me to go to Thane, a suburb of Mumbai. Bhaisaab had some foreign guests and his car was not available for me. There was a Maruti 800 car, but it was too small to take my wheelchair. I decided to take a taxi. The Cheshire Home was on the way and I wanted to stop by and tell my fellow brothers that I hadn’t forgotten my promise. But I was getting late and stopping en route would mean extra waiting charges for the taxi. It was June and raining heavily.

As I was getting ready, I mentioned all this to Rehana. She said, “Get ready, I’ll see if your wheelchair can go into the Maruti.” She went downstairs. Her elder daughter, Humra was to come with me. Rehana said, “You can take the front seat and Humra will squeeze in at the back with the chair. The car is yours and you can do whatever you want. Besides, we’re all happier when you are with our *own* driver.”

Music to my ears! It was still raining when I reached the Cheshire Home. Was I imagining or were they not happy to see me? Maybe I felt that because I was guilty about the wheelchairs. Maybe they thought I’d conned them. Besides, from March till June, I hadn’t bothered to meet them or even to write to them.

But Chandrashekhkar took me aside and said, “No, it’s not you. They’re all sad about Narendra.”

“Huh...Narendra?” I asked.

“Yes. You see, after he came back from Kolhapur he had high fever and vomiting. They couldn’t figure out when the

electrode fitted in his throat was expelled. But since then he can't speak."

"Oh no, not again!" I shuddered.

Narendra's present condition saddened everyone at the Cheshire Home. He was their inspiration and joy. He withdrew from everyone and shut himself in his room. Though it was getting late I couldn't go away just like that, I had to make an effort to see him so I gathered courage and sent him a message—"May I come in?"

"I'll see you soon," the message came back.

I held my breath and my heart beat fast. The conversation would be one-sided since he couldn't speak. Within a few moments I saw a figure wheel himself towards me, one hand on the wheel. Good God! Was this actually Narendra? All I could see was a gaunt figure in a wheelchair, unshaven, long-haired. I couldn't believe it! I couldn't bear to give him more than a glance and I had no courage to meet his eyes. How could I even say a simple "How are you?" I could see how he was. In fact, what could I possibly say? I had neglected him, not offering him solace or encouragement...nothing. I bent my head as I felt that familiar catch in my throat, tears pricking my eyes.

"Oh, I hate tears. But I do look like a wild animal, don't I? I'm nothing but an animal in a circus. So I oblige them, acting like an animal till the spectators are satisfied. By the way, I'd written a letter to you, but didn't feel like posting it. Here it is, but oh, please read it at home, not here!" Since he couldn't speak, he kept scribbling all this on a pad with his left hand holding a pen in that contraption of his.

"Okay, goodbye for now, I'll come again, later," I said and left.

I couldn't wait to get into the car and read Narendra's letter. It was still pouring. I know he's going to get livid with me for publishing such a personal communication, but unless you read it, you'll never know why I threw myself into rehabilitating Narendra. It read:

Didi,

*Jagat Didi*, everyone's elder sister, you may wonder why I'm addressing you thus. But you see, everyone knows

you by that name and it's your identity. That you are called "Didi" has come to mean a special thing for me.

Coming to Kolhapur was a special experience for me because I learnt a lot. I noticed the close bond between every member of Helpers of the Handicapped. There was a strong desire in each person to be his or her own master, to achieve something. It was so exciting for me to see that.

When I left the hospital after my coma, I was a living corpse. I'd lost everything including my memory. But I had hopes that one day, with my self-confidence and perseverance, I would be able to take life head on. I started a new life, started to learn things. The doctors told me that I was one hundred per cent disabled but my determination to get better proved them wrong. You may not guess, but I'm writing this letter with the help of a device made by me because I cannot hold a pen. But where has my strong will taken me? Was the Cheshire Home to be my only destination?

Didi, I've been here for the past one and a half years. But I'm restless. I want to do something, learn something. I've been talking to a lot of people about my rehabilitation but no one wants to help. Here in Mumbai, they're ready to give charity but don't want to empower anyone. Helen Keller...oh she's always everyone's role model, but no one gives us a chance to be like her. You can probably understand what I'm saying because you must've felt something like this yourself. Here is a poem that I wrote while I was at the hospital:

*I may succeed perhaps  
Or may be ruined  
But someone will say  
He really tried  
He lived indeed!*

Little did I know then that it was to be a dream that would end at the Cheshire Home. I've nothing against the Home, but to me it's nothing but a free prison for those who are physically and mentally defeated.

Really Didi, there's not one person here who wants to be independent. They've come to terms with their



situation and have given up on life. But I hate it...I will either do something or free myself from this imprisonment.

So I'm leaving Mumbai but with no destination. It will emerge, I'm sure. But I do have a request for you. Please don't be a lighthouse only for Kolhapur but shine like the sun. I wanted to talk with you before you left Mumbai but I had high fever and vomiting. It was so bad that the electrode in my throat which the American doctor Penceford had inserted through microsurgery, slipped out. Since then I've lost my voice. No no, don't think that I'm shattered because I've lost my voice, Didi. By now I'm prepared for anything. I may come to Kolhapur before July 31, I'd promised Renuka Didi of the Datt Mangal Karyalaya that I'll come to Kolhapur one last time.

My regards to Renuka Didi, Mr Deshpande, Mr Deshbhratar, Rajani Didi and everyone at Helpers of the Handicapped.

Narendra Sharma

I wiped my eyes. I was dazed by the time I reached Thane. My detour to the Cheshire Home made me late and Suneeta was waiting for me. She'd kept lunch ready and though I was in no mood to eat, I did just so as not to offend her. I gave her the letter and now that I was in a private space, I cried freely and bitterly. Poor Narendra, how lonely he must be!

Suneeta consoled me, "Come on Naseem, stop crying. We'll find a way out, let's not give up. If he agrees, we'll take him to Kolhapur for a change."

"Hmmm....not a bad idea," I thought to myself.

I made quick mental notes. Now that our training centre was shifted to Kadamvadi, we converted the spacious flat in Atmaram Building into a guesthouse. The kitchen was now fully functional with utensils, towels, napkins and soap. Narendra could stay there. I planned to recruit Ramdas Sonavne's mother, who was now working at the training centre, to help him.

I stopped again at the Cheshire Home on my way back. I couldn't possibly tell Sister Pushpa about Narendra's letter.

So I told her, "Sister, I was thinking that Narendra might

do well with a change. How about we take him to Kolhapur for a bit if it's okay with you?"

"Aha!" Sister Pushpa said, "But you know Narendra is very adamant and he has his whims. If *he* agrees to go with you *I've* no problem."

Somehow I didn't feel like descending the stairs and going in the dark to meet him. So I asked my nephew, Arif, who was with me and Humra, "Will you take a letter from me to him tomorrow?" He nodded.

I went back home the next day and soon after that, Arif went to a lot of trouble getting Narendra to Kolhapur.

It was audit time at Helpers. PD, Abhijit, Nalavde, Telang and I attended our offices during the day and did audit work at night. But when Narendra arrived, I took leave from work.

I was keen that Narendra should be examined by doctors to see whether he could get back his voice. "Why bother?" Narendra said in his typical fashion. "There's nothing anyone can do."

I still took him to two ENT specialists in Kolhapur. The verdict was loud and clear, Narendra would never speak again. Still we had long chats. I talked and he wrote. His hand was probably aching from writing answers to all my questions. I was probably the only one who had so many anyway. But I was getting somewhere with my investigations. He told me how a couple of journals carried articles about him asking if there was anyone who could identify him. One day, there was a response from a certain driver. According to him, Narendra had studied in Sweden, where he lived with his grandfather. He was in Delhi for some research work where he had his lab, a farmhouse and a car. So Narendra hoped to get back his memory by visiting Delhi. He might be able to locate a bank account or some other possible clue.

So I asked him, "Shall we go to Delhi after the rains?"

He wrote, "I find it impossible to start a new life unless I put an end to questions about my past."

I telephoned PD and asked him if I could be excused from the audit responsibilities. When everyone agreed, I decided to go to Delhi immediately.

I asked him, "Narendra, suppose you get your memory back, what would you do?"





"I'll spend my life helping disabled people and if I still have my bank balance and flat, I'll continue with my research."

"And what if we are not successful?" I pushed.

"Then I'll look for someone to sponsor me to do research in the fields of Muscular Dystrophy and Multiple Sclerosis." I don't know, perhaps Narendra was probably some sort of genius.

We left for Delhi without even bothering about my return bookings. As usual, the Deshbhratars, who followed me everywhere like a faithful shadow, came with me. Sometimes I wondered how they managed their jobs or even their children's schooling.

We scoured every nook and cranny in Delhi for fifteen days, hoping that some of the blocked and hidden passages in his brain would open up. We had some luck but only up to a certain point, beyond that it was a blank wall. We even enlisted the help of a detective agency. Then we tried using the media—Jain TV, Doordarshan and *The Times of India*. My friend, Pramila and her husband Mahinder gave us their unstinting help, as few would ever do, with either one of them accompanying us everywhere. Narendra's face was ravaged with despair and my heart grew heavier by the day just seeing him. I prayed like I never did. More than anything else, I wanted to see him united with his family and home and get his career back. But with every failed attempt, our hearts grew weary.

Narendra was exhausted and wanted to go back. On 31 July 1994, he announced, "Enough! I'm fed up! Now I'll not go anywhere even if some of my relatives turned up." Even a lost dog is found within eight days, but he'd lost his family eight years ago! What was worse was that he was losing his faith in relationships, God and humanity in general. After his illness, I was the first one whom he had addressed as "Didi." Now even his Didi was letting him down, he had no hopes from her too. I was helpless, but I could guess only too well what unimaginable torture he must have gone through all these years.

I'd made up my mind that either Helpers or I would adopt him. But would his pride allow us to make such a move? After much persuasion we were able to bring him to Kolhapur

on 23 September 1994. But before that, destiny dealt him another cruel blow in the form of an attack of Multiple Sclerosis (MS) and this time his spinal cord and hand were badly affected. But the indefatigable Narendra still managed his daily routine himself. He'd declared war on destiny!

As he used one arsenal after another in his war, I wanted that his saga should be filmed for all those disabled people who were hurtling down the dark tunnel of gloom and whose morale had hit rock bottom. Dr Ragini Jain and Mr Ram Gabale from Jain TV were only too glad to do the film, but Narendra being Narendra refused. He never wanted to be an object of pity as he surely would.

So now he was in Kolhapur. Now that he was here to stay, we had to find him something challenging to do. We appointed him Supervisor at our training centre. It wasn't long before we began to see changes. He used his sharp analytical mind to re-design our instruments and appliances including calipers. Quality and quantity both picked up. Now he started telling us that it was time to patent his hand-appliance and the other instruments he was creating. The patent rights should rest with Helpers. His hand-appliance was particularly useful for leprosy patients who could use it to eat, write, shave and shower. So on World Disabled Day we distributed them to twenty-two lepers.

Narendra's designs, including calipers, were clearly working and now it was a matter of having it endorsed by the Bureau of Indian Standards. Once ratified, we could have it mass produced thus generating employment for hundreds of disabled people. First the ratification and then fund raising to begin production—that was our plan. We also owned some land in the industrial area of Shirol which we could use for a workshop. It was situated near our gas warehouse.

Meanwhile the war between Narendra and destiny was raging. His determination and his enviable optimism never flagged. He was clearly winning. And just when we thought destiny was vanquished forever, it employed another trick, another deadly weapon. He had another MS attack and was unconscious for three days. He writhed in agony and his sunny nature was under siege. I couldn't even cry in front of him because he "hated tears." And then it struck again,

snatching away the strength of his jaw. Now he couldn't bite, chew or swallow. But on the fourth day, he was back at work in his wheelchair, working like one possessed. He treated himself with exercise and medicines. Gradually, he was able to swallow a little bit of mashed rice. His breakfast consisted of cooked semolina, soft Maggi noodles or vermicelli. At noon he drank cold buttermilk, milk or coffee. And at night he ate a little rice and dhal. He lived all alone and insisted on cooking for himself, having dismissed Ramdas's mother earlier. He had a railing constructed on the ramp to the workshop so that he didn't have to be pushed up and could come and go without anyone's help. Now we were waiting for him to start speaking any moment. He busied himself trying to make a fiber caliper. Since he was now living in Atmaram Building, we made a small lab for him there with the help of Anutai Bhagvat, Desai Kaka, Mohan Dada, Shirgaonkar, Sharad Samant and other reputed doctors who supported us financially and with advice in ways that can't be described in words. As for me, I put in all my resources—physical as well as financial—to encourage this intrepid researcher survive his cruel lot and keep his spirits up.

But destiny was plotting again, this time with a weapon deadlier than all the rest. Narendra's eyesight was getting weaker by the day. There was the distinct possibility that MS could render him blind. If that happened, he said he would leave. The last thing he wished for was to be a burden on us.

I'd failed as a sister to him. But could I at least be his mother? Perhaps I could legally adopt him and therefore be entitled to do his last rites according to his wishes when he died. I consulted a lawyer only to be told that the law wouldn't allow it since I was only about ten years older than him and also because both of us were disabled.

I couldn't give a home to ten-year-old Prakash Joshi when he most needed it. Now I could give Narendra a house of bricks and mortar but not a "home." What I wanted to do more than anything else was to make such a "home" for the innumerable Prakash Joshis and Narendras who had nowhere else to go. But I had no one to turn to except God but why was He taking so long?

Narendra had eloquent thoughts though he couldn't

verbalise them. So for our various events, he used to write them down and I used to read them out. On one such World Disabled Day he wrote:

Respected guests and friends,

This is the second time, at the same place and same occasion that I'm putting down my thoughts before you. It is World Disabled Day today but for me, it's the day on which I fought with death and became disabled. Who else but I would know what a disabled person goes through, physically and mentally?

Today, we felicitate the late Rajan Deshpande with the Great Flight Award. He was my source of inspiration. I made it a point to visit him whenever I went to the Sion Hospital or the paraplegic foundation in Mumbai. But it was like this,

Behind the veil of smiles

Is hidden a pathetic tale of unspoken grief.

Rajan Deshpande, though extremely disabled, was hard working, determined and put up a brave fight with a smile on his face. But to me he represents the result of societal complacency, government apathy and the withering away of talent. He was a textile engineer, but instead of working in a textile mill he was grounded at the paraplegic foundation trying to paint with a brush held in his mouth.

Today, I would like to challenge every upper and middle class family of our society. If each family would adopt one economically disadvantaged disabled child, educate and rehabilitate her or him, our problems, not just in Kolhapur, but the whole of India would be solved. Only then can we call this day World Disabled Day.

When I was living in the Cheshire Home some college students visited us to do social service. They belonged to wealthy families where they were probably so pampered that they never had to wash their own glass even once. But they handled us with so much care. Why? What did they get out of it? I believe it's something that they could never buy in the marketplace, satisfaction and mental peace.



Social service is something sacred, an act of penance for all our blessings. It is our foremost duty towards society, nation and humanity. I find the people of Kolhapur warm hearted and affectionate but with little sense of direction. Isn't that why Helpers of the Handicapped has such few volunteers? It needs funds and people or its dreams will die even before they're born.

When I look at Naseema Didi, PD Deshpande Sir and Mr Deshbhratar and their families working here, I can't but notice the shine on their faces even when they are exhausted. I appeal to all of you to give a little of your valuable time to Helpers without expecting anything in return. We can reach the sky but only with your help. My incomplete poem would then be complete:

I will create a sun out of a firefly...

Today, I hand over all copyrights and patent rights to Helpers of the Handicapped for whatever I have invented—appliances for eating and writing as well as the fiber glass calipers. I would like to see them supplied all over India and bring a smile to every miserable disabled person. I seek your love and cooperation.

Thank you.

Soon, funds for the Uchgaon hostel ran out. We had no more money to give the contractor. We'd intended to start the hostel by June 1995 so that our students could continue with their education. Now it didn't seem possible. Then we found a way out. We could temporarily use the hostel at the training centre in Kadamvadi for school students. There were eight such children (five boys and three girls) who would have had to discontinue their education if they had nowhere to stay. There was Mohammad in class three who didn't have both arms. Then there was Bandu also in class three, who'd laid our foundation stone. His father belonged to a wandering community of shepherds. Sunanda Mohite, who was in class twelve, had no father and suffered from acute arthritis and couldn't move her limbs. Shobha Gurav in class seven had polio in both legs. Tai Badke, in class five, was very short and had brittle bones. Prakash Gosavi, in class

three, was disabled since birth and walked on crutches. And there was Shobha Kamble, in class five, who was very short and mentally retarded.

The children started attending school. Mohammad was refused admission in the school just opposite the hostel, but the Korgaonkar School gave admissions to all our students. They even moved their classes to the ground floor.

On the day that Mohammad came to live in the hostel we had dinner with him.

Narendra happened to be with me. We were both upset to see Mohammad eating with his feet and talked about it all the way home. That very night, Narendra sat up making an artificial hand for Mohammad. By morning it was ready. Mohammad now eats with his artificial hand. How fortunate for me to have a colleague like Narendra! Still I knew that his real capabilities lay elsewhere.

We had many patients who suffered from Muscular Dystrophy. It was so painful to disclose to them that there was no remedy yet. When it strikes, deterioration is rapid. Narendra told us that a particular kind of diet could prevent it from getting worse, but he needed the consent of the parents of such patients before he could experiment with it. We called for a meeting of the parents. About five such parents gave us permission. The diet was quite expensive, but Abhay Doshi, who lived on the upper floor, volunteered to take care of the expenses and thus we started our experiment. Rajendra Ghorpade who underwent this treatment now conducts classes in his village. Another young man, Santosh Brahmadahe lives in the Uchgaon Hostel and is in his final year BA. It's not as if he's free of all problems, but he hasn't lost heart. He was declared "Ideal Student" and wins prizes for elocution and painting.

We had to face many problems trying to maintain the "hostel" at the training centre in Kadamvadi. I spent many nights there, sleeping on a bed behind a partition. Before I took any decisions, I had by now, acquired the good habit of getting a first hand experience of the problem. So even before the students mentioned it, I was aware of it. The windowpanes were broken and water came in during the rains. To save money, we covered the broken windowpanes with plastic



sheets. In winter it became bitterly cold. Polio patients are very sensitive and can't withstand even the normal cold. As for me, even a little bit of cold weather was enough to freeze my hands and feet and turn my nails blue. I spoke to Dr Gune about the cold problem in winter. True to his nature, he promptly sent us forty blankets of the best quality.

The problem of the cold was thus solved, but now we had no money for food for so many people. My salary and the meager donations we received put together still didn't meet our needs. What were we to do? How could we go to the same sources again and again for money?

Once, the situation became so critical that I had to do something I'd never done before. After dinner I asked everyone to gather around. I said, "Can you lend me, if you can, whatever savings you can spare and I'll return your money within fifteen days."

The collection box went around and as they gave me the money they said, "Here, Didi, take this, don't bother to return it." Even little Mohammad and Bandu shared their pocket money. We bought provisions the next day.

Soon we got some donations and I insisted they all take their money back. However squeamish I felt about asking the kids for money, one thing was now certain, I would never be let down in a crisis, they would all stand by me.

The kids continued to surprise me. Once, as I working in my office, I got a telephone call from the training centre. "Didi, can you please come over and stay tonight? We want to talk you." I rushed there after work.

They told me, "Some people from a certain organisation visited us. They distributed fruits, bananas and apples to us and got themselves photographed with us in front of banner of their organisation. We don't want to be given sweets and fruits nor do we like being photographed. If need be, we'd rather economise on our food, all we want is for us to continue going to school." I was delighted and oh so proud of my kids!

It was so important to nurture their self-respect which could be shattered at the drop of a hat. Once, when we had a function at our training centre, a gentleman walked up to the stage and thrust a bundle in my hands saying, "Here are some

old clothes for your children." I didn't say anything then but quietly took it, feeling very uncomfortable. Don't all religions say that alms should be given but secretly? Even our right hand shouldn't know what the left does, they say; instead most donors make a huge public display of their personal contributions. Giving of alms should never humiliate the recipient. All it takes is for the donor to put himself in that position. The next day I asked to see the gentleman and explained the situation to him, gently telling him that what he had done had perhaps humiliated the kids. He seemed to get the point. I thought it would be rude to return the bundle of clothes so I distributed them anyway. It's not that we don't take old clothes and other articles, but we have them deposited at our office and therefore discouraging people from giving them directly to the children. Then we sort out the clothes and give each one what they need, making it a point to tell them that they have to pass on this kindness when they start earning. We say, "You mustn't feel shy to take help but remember to help others in the future as they have helped you."

One day, Abhijit Parab, a young boy, turned up at the hostel in Kadamvadi. He had polio and used calipers and crutches.

"I have no one, no parents or relatives," he said. "My landlord threw me out. Someone gave me this address and that's how I'm here. Please let me stay here." He looked so pathetic that we took the poor orphan in. But the clothes he wore, his wristwatch and shoes told another story. So I asked Desai Kaka in Mumbai to make some inquiries based on the address that the boy had given us. It turned out to be a wrong address and there was no one there with that name.

Then, one day, Abhijit ran a high fever and in his delirious state he muttered things which gave me a clue that the boy had lied to us. I had to track down his parents somehow.

When his fever subsided, I patted him gently on his head, and said, "Look Abhijit, you must tell us everything. Lying will only get you into trouble."

Then it all came out, "I have a family, parents. I was studying in class eight. My teacher beat me because I misbehaved with a girl and I ran away without telling my parents." I wrote to his parents.



While all this was going on, we discovered that Abhijit had fever because he had typhoid. His mother arrived with a posse of policewomen (who kept spitting everywhere and really annoyed me) since she'd lodged a complaint with the police. His father didn't come, apparently he was travelling. Irritation welled up in me. Where was the need to arrive there at the first instance with a battalion of cops when she knew exactly where her son was? We refused permission to the policewomen to see Abhijit who was sick, asking only the mother to go in.

When the father came finally in response to our message to meet us, I told him to try and see whether Abhijit could get re-admitted in his old school in Mumbai. But he'd already had a row with the school authorities and taken the matter to the police. So I went to Mumbai to meet the Principal of his school.

Sitting across his huge table, I said, "Look Sir, Abhijit is a young boy. Children make mistakes don't they? Please pardon him, he probably didn't know any better. Moreover, as a disabled child, he must get educated or there's no future for him."

"But Abhijit is a bad influence on the other children. I'm sorry," he said sternly.

"Then at least give him a school leaving certificate without mentioning his peccadilloes," I insisted. "I'll take him to Kolhapur to another school, but he does need this certificate."

"I'm sorry, Ms Hurzuk" the Principal's stern voice indicated that the matter was closed.

My trip all the way to Mumbai was in vain and I returned, dejected.

Abhijit lost a year. Somehow his father got him into another school and managed an honourable school leaving certificate for him. Soon Abhijit came back to Kolhapur and started going to school with the other children of Helpers. For the two years that he was with us, we ignored much of his bad behaviour. Then things got out of hand again and matters became serious when he began to really misbehave with the girls. We had to ask him to leave and handed him over to his father. He was in class nine.

Construction work in Uchgaon had come to a halt because of no funds. Our grant application languished somewhere deep in the bowels of the central government offices, maybe never to see the light of day. Simultaneously, we had applied to the Siddhi Vinayak Mandir Trust in Mumbai. Abhijit Gare suggested one day, "I know a certain Mr Taralekar in Kolhapur who happens to be my father's friend. Let's give him a copy of our application and see what he can do."

"Yes, let's," I agreed.

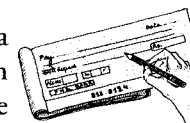
And lo and behold, soon after we gave Taralekar a copy, the Chairman of the Trust, Mr Dahanukar and some other trustees came to visit us! We took them to our training centre in Kadamvadi. Our children plucked fresh roses for them from the garden. They saw that we were somehow managing to run a makeshift hostel here because Uchgaon had come to a halt. As soon as they returned to Mumbai, they sanctioned Rs 15,00,000 for our project and we were to follow it up. Mr Taralekar had saved us! I had taken vows at the mazhar of Taj Baba in Nagpur and Haji Ali in Mumbai for our hostel and also for Narendra. Now Allah helped us through the Ganesh temple.

But Ganesh, sweet though he was, wouldn't let us have the money so easily without putting us through a right royal spin. As soon as the money was sanctioned, I wrote to the secretariat of the Siddhi Vinayak Mandir Trust. The first step was to get consents and signatures from two ministers. So off I went to meet the Cabinet Minister in the Home Ministry at his office.

He said, "Ma'am I can give you my consent only if your file reaches me from the office of the Minister of State."

So I took an appointment with Prabhakar Rane, Minister of State in the same ministry and went to his bungalow the next morning. The minister was punctual and I was the first one he met. He was happy to see our work (I had a ready portfolio of photos and papers) and said, "This is great work, Ma'am! Why don't you start something like this in the Sindhudurg District? I'll help you get land from the government"

"Great idea! I'm ready for it," I said with obvious enthusiasm.



“Well then, I’ll see to that. Oh yes, and I’ll sign that consent letter you wanted today. You can then take it to the Cabinet Minister for his signature.”

We sent in the ministers’ letters to the Vinayak Trust. Within eight days, our money was sanctioned. Now I had to go to Mumbai again to receive the cheque from the Trust office. There were no tickets to be had on the train, so we had to take an air conditioned all night luxury bus. The bus had a breakdown but we made it to Mumbai just before our appointment with the Trust office at eleven. We had hasty baths and rushed there only to find that the concerned officer was not there! I was dead beat with the combination of air conditioning and sitting up all night. Would you believe it, we waited from 11 am to 5 pm and still the officer hadn’t turned up! Sitting in the wheelchair for so many hours killed my back. I had to lie down or I would die! We were led to a waiting room where there was a big soft sofa and two smaller ones. Vishranti, my nephew and I gratefully plonked ourselves on them. The sofa was a godsend. I could now be kind to my poor back. The two of them took the other two sofas. We shut the door and slept the sleep of the dead.

We hadn’t eaten any breakfast or lunch. A kindhearted peon had peeped in once with some tea but seeing us all asleep, he tiptoed out. When we woke up he brought us some prasad (offerings of food to Ganesh) and buttermilk. After this ordeal, his ministrations were most welcome. Just as we were beginning to feel a little better, we got a call from the officer. He wouldn’t be able to come where we were, but we were to go to him at his office in Fort. So we bundled ourselves into a taxi, wheelchair and all. But could a day be so bad? He didn’t have our documents, so we had to come again early the next day.

To cut a long and exhausting story short, the cheque was sanctioned and once we opened a new account in the bank to receive it, they would send it to us. Now we had to convince the contractor that he should continue with the construction. So we took photocopies of the cheque and the sanction letter to show him. We returned to Kolhapur.

After a few more red tape hurdles, we got the funds. Construction was in full swing. But very few people had an

idea of the needs of disabled people and our sub-contractor, who was in charge of the sanitary work, was one such. So I thought a demo would be a good thing. We took him to the room where I would eventually be staying. We showed him at what height and spot the tap was to be fixed and the WC and pipes which needed to be placed next to it for me to get a good grip. As sub-contractors go, he wasn’t the best and these jobs had to be done again and again. Despite all these precautions, we realised, too late though, that the bathroom floor should have been at a lower level at a slight incline. The plumbing work took forever, and I was still unhappy with it. Did it take genius to indicate the difference between hot and cold water taps? Fortunately, the electrical work was less painful. We managed to get our switchboards installed at lower levels to suit us.

As we were getting the hostel in place, we also had to think of other things, such as some form of transportation to take the kids to school. Uncle Shirodkar worked out an application to the Life Insurance Corporation to sponsor a mini bus. I did the rounds at their office in Mumbai again and again. On my third visit they told me that all their funds were being used for a pulse polio campaign, so we shouldn’t expect any money from them that year. I was very disappointed, but then I consoled myself, thinking, “Oh well, it’s more urgent to eradicate polio in the first place than to get them educated.” In a way they were contributing to our mission.

But these repeated trips to Mumbai were wearing me down more than I can describe, so one day I told to Rajani and PD, “Look, we can get almost anything done in Mumbai if we tapped the right sources and pressed the correct buttons, so we shouldn’t give up. But though Desai Kaka helps me, I still feel very alone as I go from office to office to raise funds. I think it’s time the Committee Members took turns to accompany me.”

They agreed and we began to plan our trips. During our very first visit, Desai Kaka helped us to get funds for an autorickshaw. We had a small function at Rehana’s house where Justice VR Krishna Iyer was the chief guest. He was a well-known legal luminary, social activist and Advisor to late Prime



Minister Indira Gandhi. As he gave us the cheque, I felt overwhelmed that we were receiving it from such a great man. He gave a magnificent speech which, I regret to this day, we didn't record.

PD and Rajani came with me on my next trip to Mumbai. This time, I went without any female help. Vishranti was on leave and no one else was available. So I did everything including the washing. But it left me very tired. We already had two appointments in hand— he Drshiti Human Resources Centre and The Tata Trust. I told Desai Kaka, "Since we're coming to Mumbai anyway for these two appointments, can you try and get us some more?"

"Yes, let me try," he said, "I'll see if I can fix you up with Mr Bal Thackarey." He was the Shiv Sena leader. We stayed at the All India Institute in Haji Ali.

Bhaisaab had a good friend from Hubli. He, along with one of our donors, Mr Umarsaab helped us meet Smita Navare and Jyoti Subhedar from Drshiti. The ladies had come to see our work in Kadamvadi and were very impressed. Since then, I could count on their help whenever I went to Mumbai. This time, when we were all there, they got us an appointment with Mr Jadhav, from the Mahalaxmi Temple Charities Trust.

But oh the stairs! If there's one thing that unnerves all of us disabled people, it's staircases! We managed to clamber up, and though the temple was quite crowded, they made arrangements for our wheelchairs to be taken right inside. Mr Jadhav sent us Rs 1,30,000 for our hostel furniture. Then we went to the Volkart Foundation and they gave us Rs 2,00,000 for our training centre in Kadamvadi.

But we were still far from meeting our requirements. One thing was uppermost in my mind which I kept repeating to PD and Rajani, "Now we should try and get fifty wheelchairs so that the kids at Uchgaon won't have to crawl and drag themselves like the kids at Kadamvadi. Let's find a donor to do this for us."

It was five in the evening and we were visiting a friend. I gave Rehana a casual call. The phone trembled in my hand as she screamed, "Where were you since the morning? Don't you think you should call us at least *once* during the day? You have an appointment with Mr Bal Thackarey *now*...at

7 o'clock! Desai Kaka's so upset with you, he just didn't know how to contact you. How on earth will you make it to Shivaji Park on time? We're leaving immediately to join you there. Call Desai Kaka and don't be late!"

I put the phone down in a flap. Rehana was right, how on earth would we make it? We left our snacks on the table, half-eaten, and made a wild bid to reach there on time. It was peak hour evening traffic and our car was one of the many stuck in the jam. We could do little but pray.

It was 7.30 by the time we reached. Our hearts were pounding and our breaths were racing. We were put through the usual security checks before being ushered into the VIP's room. As soon as we entered, we saw that Thackarey was busy giving an interview to someone. But he signalled to us warmly saying, "I'll be with you shortly, just as soon as I finish this interview."

"Oh yes!" I thought to myself, "We'll wait, not just for a short time, but for as long as you want! After all, we were the ones who were late." Actually I was wondering whether he would see us at all!

He finished the interview and came over to where we were sitting. He looked through our photographs, gave us a patient hearing and asked several questions. Finally he asked, "Okay, what do you want from me?"

"We need a bus for our students, Sir."

"Done. What else?"

Our jaws fell open. We were so stunned that we couldn't utter a single word.

I had a passing doubt, "Is he pulling our legs?"

"Do you see those two gentlemen sitting there?" Thackarey asked, pointing to two men. "Meet Suresh Dada Jain and Ganesh Naik. It is wise to milk the cow that yields milk when that cow is standing at your door, they say. Go on, tell them what you need and they will give it to you."

We jumped at the offer because we knew exactly what we wanted, "Our children need physiotherapy but the equipment is very expensive."

Actually we needed equipment worth nearly three lakhs but we didn't have the courage to ask. So we said, "We need money worth a lakh and fifty for wheelchairs."



Thackarey told them, "Donate the wheelchairs to them on January 6 in Meenatai Thakre's memory. Oh, and the bus too, on the same day.

From there the matter was simple enough. We gave them the name, address and phone number of the company that made the wheelchairs. Meanwhile, we would select and buy the physiotherapy equipment and get the money reimbursed.

"But won't you need special fittings for the bus?" Thackarey asked.

Oh God! Was this a dream?

We blabbered, "We'll take forty students in the first leg of our project. The bus should be big enough to accommodate forty wheelchairs and it should have a ramp for the chairs."

"But what about a toilet? And perhaps a bed?"

This was getting too good to be true. "Uh...huh...yes, we'll design the bus." I was weak with joy. We would take measurements, work out the design and hand over the papers to Subhash Desai, MLA, at the *Samna* (a Marathi daily of which Thackarey was Editor-in-Chief) office in Mumbai.

We were still in a state of shock when we left his house. It was unbelievable and unforgettable! Thackarey had given us so much of his time and attention and I might add, invaluable support to Helpers.

Desai Kaka always preferred to take backstage. He doesn't like it when I even mention his name. But it was thanks entirely to him that we met Mr Thackarey. We were overwhelmed, blown and dumbfounded but pleased as hell! Taj Baba had answered both my prayers and I made a mental note to visit his mazhar soon and place my gratitude there. I also wanted to visit Baba Amte at Anandvan again.

Meanwhile, Narendra continued to work at the training centre during the day and at night he was busy in his lab. He barely slept for three hours. He managed everything on his own—bathing, cooking and so on. Very often he ate nothing, saying, "Oh, don't you know, our body has reserves of energy. You needn't eat everyday." But though he was so spartan with his food, we always thought of him whenever there was special food at home and had it sent across to him. But when it happened one too many a time, he got furious. Then I had to hold myself back.

My folks teased me, "Naseem, serves you right! We all know Narendra is your darling, your dear child, surely you don't mind him getting a little angry!" I don't blame them really, for often I relaxed my rules when it came to him. I wished with all my heart that he should be able to speak and hear without the hearing aid. Perhaps I was only fooling myself because Dr Hiranandani from Mumbai had told me and Anutai categorically that he would never be able to speak.

But one day he surprised us all. His experiments showed some results and he was going to demonstrate before us—by speaking a few words. PD, Deshbhratar and myself and also Ma (Narendra wanted that) trooped off to his apartment. He seated us all down and then with what was clearly a herculean effort, he uttered a few words "Ma, Didi, PD." We were delighted.

"Narendra, that's fantastic! You did it!" I clapped my hands. "You must do a demo for our trainees at Kadamvadi. We'll record it!"

Our trainees were delighted. And would you believe it, this time he could actually speak a few sentences!

What none of us knew was that Narendra's life was to change dramatically. One day, he met Vineeta whose eyes brimmed over with tears when she heard his sad story. He met her on a trip with some friends to the Rankala Lake. They became friends and then their relationship blossomed and soon Vineeta was ready to share his life as his wife. Narendra needed a companion so badly, not only to care for him, but also to practice his experiments to speak normally. It was Vineeta who proposed and he said yes. Then he told me. Even as I was recovering from this most pleasant surprise, I gave Vineeta a complete background about him. She seemed to have a large heart for she wanted to take him just as he was.

I wanted to be completely on call for their wedding, helping them in every possible way. But as luck would have it, just around that time we managed to get a hydraulic bulldozer for levelling the land in Uchgaon. We had been struggling to get one for a long time, and now RD Patil was offering it to us free of charge! But the condition was that we





had to complete the job within a stipulated time frame. Though it was all happening in the same week that Narendra was getting married, I had to agree because we were about to save a whopping two lakhs. I therefore had to give all my attention to this even as Narendra was getting married. Rajani, my dear friend would be my best substitute, so I passed on the responsibility to her. I put my signature on their marriage certificate as his guardian. The religious ceremony was taking place at our training centre. I left the bulldozer briefly to reach there at the last minute to shower rice on the bridal couple.

Just as we were about to sit for the wedding dinner, Dilip Rhotal, a trainee who was supervising the levelling, called me from Uchgaon. It was ten o'clock.

"Didi, as soon as you left, the driver of the bulldozer stopped all work. They're taking the bulldozer away! And they just won't listen to me," he sounded panic stricken.

And that was the end of my dinner which hadn't even begun. I rushed with Deshbhratar in a rickshaw. It was very cold and I was exhausted. I called Patil since the driver was reporting to him.

"You stay right there till the job is done, and don't you dare move the bulldozer till they let you go!" Patil was furious as he told the driver.

Just two days ago, some people from the locality had stopped us from levelling the land. We had to stop work for two whole days. The whole affair made me sick. Once again, I had to do something I hated doing—disturbing someone at home at an odd hour. I had to call the District Collector at his residence at night and request him to give us police protection since the locals were getting unruly, preventing us from using the bulldozer in our own land. After Patil's firing, the driver was ready to work through the night. The Collector consoled me, "Don't worry Ma'am, the Revenue Officer will help you out in the morning. No one will trouble you after that." He'd already seen our papers and maps and I should have felt reassured. But why was it that I couldn't sleep all night? Now here was the driver giving us a fresh dose of trouble to deal with, I groaned.

Deshbhratar and I kept vigil at Uchgaon the whole night, reaching home at dawn. All I wanted was a hot bath and breakfast and to hit the bed afterwards.

The phone rang while I was still in the bathroom. It was five in the morning. I heard Ma pick up the phone.

"Hello," she said. "Hello, Hello," she said again.

"Who is it Ma?" I shouted from the bathroom.

"Don't know," Ma said, "I can hear someone coughing, that's all. I think it's Narendra from Atmaram."

"Huh...Narendra? Why wouldn't Vineeta be speaking?" I was puzzled.

"Naseem, all I can hear is this infernal coughing," Ma said.

Something had to be horribly wrong. I rushed out of the bathroom, got ready and stepped out into the rain.

"Naseem, wait...you can't..." I heard Ma in the distance as I sped away in a rickshaw with my nephew.

Narendra had a note ready for us to read, "A squad of goons have take Vineeta away at knife point." Narendra, never a great one for tearful sentiment was openly crying now.

"Shame on me," he kept writing again and again. Obviously, he blamed himself for not being able to protect his wife.

"Think, Naseem, think..." I said to myself. "Think quickly or all will be lost." Suddenly, like a bolt from the blue, I found myself thinking of Dr Sunilkumar Lavate. He is not only supportive but quick and influential too. I registered a First Information Report (FIR) with the police and went straight to Dr Lavate's college. He took me to meet the Deputy Superintendent of Police. Calls were made, heels clicked and wheels turned. By eleven, Vineeta and her kidnappers appeared at the Shahupuri police station. Vineeta came with us. But before that the cops beat up the goons so badly that we asked for them to be set free. I'm sure they thought that I was a bit soft in the head.

So what was the story? Vineeta had a man who loved her, but sadly for him, unrequited. So crazily was he in love that he arranged for her to be kidnapped. Now he found himself behind bars.

"I think he should be released," I said, rather gingerly, fearing that I would be thought of as insane. "After all he did this for the sake of love."

"Yes, let him go," Vineeta and Narendra both agreed.



But here was an enraged lover at large and I was the snatcher of his happiness. I was the recipient of several acerbic phone calls.

"Who do you think you are? Just because you want to rehabilitate a disabled person, you can't destroy the life of a pretty, healthy girl! How could that cripple ever make her happy?" the bile dripped from his voice.

"My dear young man," I patiently used to say, "it was *their* decision, not mine. And they are not minors that I should be responsible for their decisions." "And," I added emphatically, "how can you say that there's only *one* way to be happy, and that one way is *yours*?"

The threatening calls and letters continued but I stopped worrying about them.

Narendra and Vineeta were anxious to make a peaceful life for themselves. A quiet hill station seemed to be the best solution. I decided to support them on this, because it was my nature never to back out once I took up something. Deshbhratar and I took leave. Now I needed some money to settle them, but from where? I would borrow from my provident fund claiming illness, but Dr. Mohanrao Gune refused to give me a medical certificate. Provident funds were for what unexpected turns providence might take, he believed. Dr. Gune must have certainly had my interests at heart, but frankly, I live only for the present. Tomorrow I may be gone and then my provident fund would come to naught. But no one agrees with me on this. I persuaded Dr. Savani Chougule to give me a medical certificate and took a loan from my PF. Helpers gave me some money too and soon we were all headed off to Delhi.

We hired a matador van for Haridwar, a centre of pilgrimage at the foothills of the Himalayas. Armed with faith and little else, we arrived at a small dharamshala for pilgrims. There was an elderly Buddhist couple sitting outside. As luck would have it, they had a room with a kitchen and toilet and bath that suited our needs.

We had to seek refuge in half-truth, "You see, Narendra will stay for two or three months, he's undergoing some treatment." We carefully skirted any mention of his experiments. The good couple immediately agreed and took

them on for a rent that was virtually free. We paid up and took the receipt.

It was an unusual way for Narendra to begin his married life. I couldn't stay for long because I had to go to Mumbai to attend my niece's wedding. I felt my eyes moisten as I said goodbye to him. When would we meet again and in what condition would both of us be? Would he start speaking? Was I destined to meet a blind Narendra?

"God be with you," I whispered to myself as I got into the matador van.

Neeta and Deshbhratar were my pillars of support and without them I wouldn't have been able to do anything however hard I tried.

Narendra...Narendra... that's all I could think of on my return journey to Mumbai. How dynamic he was and yet how cruelly fate had struck him down! Why? It would always be a mystery. Why did his folks never bother to track him down? Did they want his money and inheritance? Money...money...an evil necessity, that's what Desai Kaka says, always refusing to touch money. Money is like poison, he keeps on saying.

I de-linked myself from my random and unstructured chain of thoughts as the train pulled into Dadar station in Mumbai. Deshbhratar leapt down from the train with my wheelchair. Then he niftily climbed back in and pulled out the luggage. Neeta, Nikki and Vineet also disembarked and just as I was getting ready to be lifted down, I handed over my handbag to Neeta. Deshbhratar scooped me up and had one foot on the step of the train. Just then the train moved. Deshbhratar was about to fall down into the gap between the train and the platform with me in his arms. Luckily, (miracles do happen), several sets of arms pulled us back into the coach. I flopped back on the seat, aghast at what could have happened. Someone pulled the chain which was meant to stop the train, but it only picked up more speed!

Deshbhratar and I reached the last station on the route and I was minus my wheelchair. We had to now literally think on our feet. Returning to Dadar station as quickly as possible where Neeta and the rest of the group were waiting was the



only solution. No point trying to get a wheelchair, it would only cause more delays.

"Hey, coolie!" Deshbhratar summoned a porter. "Can you give the lady a ride on your luggage cart?"

"Eh, ride...lady?" said the porter, a bit amused. No lady had ever ridden on his cart before. But when he saw my condition his amusement turned to sympathy. He hauled me on to his cart but I couldn't sit without a back support. I don't know what I did, perhaps I did sit after all, or lay on it, a petrified bundle, God knows.

The cart stopped at the taxi stand.

"Oops! No money!" Deshbhratar announced. I realised Neeta was carrying his money and my handbag.

"Listen bhaiyya," we told the porter. "We don't have any cash. Why don't you come with us to Dadar station and we'll pay you."

"Ho ho, very clever, aren't you?" the porter laughed. "Just borrow from the taxiwalla and you can add the amount when you pay him."

We felt sheepish, it was so simple after all. Why didn't we think of it?

The curtain came down on the drama and soon I was home for my niece's wedding. Ma and my sisters kept everything ready for me—clothes and jewelry. I was warned to put them on without making a scene. Though I didn't like the fuss, I agreed. After all, I couldn't participate in an earlier wedding function because of my trip to Delhi, where, to make matters worse, I'd gone without taking anyone's permission. But no one was cross with me.

Since Narendra had left for Haridwar, the responsibility of the Kadamvadi training center fell on me. Once in a while I made a call to Haridwar and asked him if he needed anything. One day, a very memorable day for me, he came on the line himself and spoke a few sentences. Narendra had trained himself to speak! Anutai and Sujalatai happened to be there. Anutai, who had a giant share in his success, had written a book titled *Mukti* (Salvation) and we were preparing for its release.

Once Narendra had to go to Delhi for some treatment. Our old friends, Mahinder and Pramila were generous with

their help yet again. They rented a flat for him and Vineeta. By now he could speak fairly well. In fact sometimes when he visited Kolhapur, I didn't have to be his vocal chords and go with him everywhere.

Finally (ah, finally), the hostel was completed and since we loved functions and ceremonies, we were eager to fix a date for the inauguration. Narendra, along with all of us, worked day and night. He got the training centre staff to work at nights and personally supervised the toilets and saw to it that they were disabled friendly.

We had a house (or should I say "hostel") warming ritual conducted by Shreekant Kekde, a trustee of Helpers. His wife, Namrata, (who was disabled herself, but eventually recovered), began teaching English on Saturdays and Sundays. Mohammad Sheikh declared the hostel open by lighting the lamp with his feet. We were blessed by several important people of the town and associates and friends. And loveliest of all, this time I didn't have to read out Narendra's speech, he spoke himself.

Once the most unpleasant task of winding up the function was finished, I would go to Taj Baba's mazhar to offer my gratitude as I'd vowed earlier. Then I would also go to Anandvan and relax for a day or two. Sonatai Patil, who'd recently joined us, was given charge of the hostel. This time I planned on taking Surekha, a disabled girl who assisted Mukta the main cook, as my helper. I wanted her to see Anandvan and also to discover how two disabled people could be of mutual assistance to each other.

I was all set to go. Just before my departure, Narendra gave me a real shock by saying that he wished to leave Kolhapur forever. Apparently, Pramila in Delhi had said some thing that hurt him and he was punishing me for that. But worse, he wanted to leave *immediately*, not even wishing to wait till I returned from Anandvan. I agree that Kolhapur was not the best place for a highly talented man like him and it would be selfish on our part to appropriate him for Helpers. Both he and I always had a tacit understanding that one day he would leave. But now I was hurt because of the manner of his departure, not even meeting me before I left for Anandvan. So I consoled myself—a meeting would've



been difficult anyway, we would both have been highly emotional and broken down, so it was just as well. We were delighted that he was now independent and happily married, but the knife turned in my heart as well to know that I may never see him again.

I was on extended leave without pay from my job for over a year. I couldn't get back to it till I'd somewhat settled the hostel at Uchgaon. I had to set a routine in motion. We employed able-bodied men but we discovered, to our horror that they behaved in a most unsavoury manner. They tortured our little disabled children physically and heckled them so that they were mentally upset. They even took away their pocket money. We asked Lavate Sir what to do. He suggested that we send away all those men within a month. Then we called a meeting of the children.

"Who is ready to help us run the hostel?" we asked.

"We all are!" they chorused.

"Okay, then we'll all jointly run it," we said.

Sometimes I went on rounds at odd hours of the night. We'd already made a rule that we wouldn't latch the main gate at night. Only the main door to the women's section was to be locked from the inside at night. Soon Avinash Kulkarni and Sonatai Patil took over the night rounds. Avinash, from Satara, was an engineering student who had once gone on a picnic to a dam site with his friends. As he was taking photographs, he fell down the dam and became a paraplegic like me. But he didn't lose heart. He completed his course and began to look for a job but since he didn't get one, we took him on as Manager of our training centre

Then we employed a driver for our hostel bus. But he used to drink heavily and often got rowdy. Once PD and I were working late at the Helpers office when Sonatai called saying, "Can you hurry over? The driver's drunk and I can't control him!"

"We'll be right there, hold on," I said.

PD and I rushed to Uchagaon and apprehended him. He was dismissed on the spot. It was too risky to have a drunk driver in a hostel for the disabled. So when I was away in Anandvan, Deshbhratar and PD appointed Gulab Sheikh who is still with us. He is sober and works hard. He is affectionate

with the children and doesn't mind if we engage him for a few extra hours.

I have to now tell you the story of Vishal.

Vishal always wants to sleep near me but, in my condition, I was unable to put his head on my lap and rock him to sleep as a mother would have. Vishal's mother was a diabetic and too young to be married. Still, as it was customary that sisters should get married before their brothers, she was married off. Soon she had a child, Vishal, with several genetic disorders. He had a short leg and only one kidney. The husband rejected both his wife and child and walked away from home. Her brothers started plotting about leaving their sister and her deformed child in some temple. If the two of them continued to stay with them, their wives would protest. So Vishal's mother had come to us at the now set up Kadamvadi hostel. We gave her shelter and she joined a nursing course. Vishal was given treatment and he started improving.

It was Rakhee, the beautiful festival where brothers pledge to look after their sisters. Vishal's mother's brothers called her home for the festival now that she wasn't a burden on them anymore. It was obviously just a façade, a sham.

"I would like to go home for Rakhee," she came to me asking for permission to go.

"But weren't your brothers planning to abandon you in a temple?" I asked sarcastically. "Why do they want you now? Do you have no self-respect?"

She stood there, mum.

"I'm sorry," I continued, "I can't give you permission."

"But...but," she stammered.

"No buts. If you go, never come back here," I warned her, sounding very firm.

She did go and I struck her off our list. She kept calling me again and again, week after week, but I stood my ground.

Three years went by. One day, an elderly woman came home with a three-year old boy.

"Please take this child in, his parents are dead. I am his



grandmother, his mother's mother. We are very poor. My husband is disabled and I have my old mother-in-law to look after. They've been telling me to dump this boy somewhere, anywhere. 'If you can't find a place, just throw him into the river,' they told me. His mother is a diabetic."

"Uh..huh...diabetic?" It seemed to ring a bell. "Does the boy have just one kidney?"

"Yes," she said, "in fact, it was *you* who killed his mother three years ago by chucking her out. You have a responsibility towards Vishal. Here, take him, then." Her tone suddenly turned vitriolic and she pushed the little boy towards me.

"Take him? How could we take on such a little boy without his mother? We're all disabled here," I said, shocked by the old woman's accusation.

"Is that so?" the woman's voice rose. "Very well then, I have no alternative but to throw him into the river."

All this happened during my lunch hour and I had to get back to work. But I did take a moment to go through his earlier papers. Our social worker had put a remark on his file that he was retarded. Now I watched him sitting quietly, eyes devoid of any expression. Indeed, he did look retarded.

The clock was ticking and I simply had to get back to work. I had no time to think in order to take a decision. There were some urgent matters awaiting my attention. The pressure was building up and I was disgusted with the old woman, the retarded child, the blackmail, everything.

"Very well, do as you please. Mind you, this is the end of this matter," I said, not looking directly at the child.

Back in the office, I got busy as usual and Vishal was furthest away from my present thoughts. It was already six so I took the hostel bus to Uchgaon. No sooner had my chair touched the ground than I was mobbed by the kids with their usual complaints and demands. I felt my blood pressure rise along with my temper.

"Kids! I like this, I really do," I said in anger. "How about getting me some tea and letting me rest a while before you bombard me? Why can't you wait for at least half an hour?"

"Sorry Didi," they said as they trooped off to their rooms with long faces.

I took a couple of deep breaths and took stock of the situation. My normal patience had run thin and I was flaring up without reason at these innocent kids. Suddenly I was sorry. It wasn't fair to expect *them* to understand my problems. How stupid I was! I was taking out my anger towards Vishal's mother on them!

At night, as I lay down on my bed, exhausted, I kept seeing Vishal's sweet face. I dozed off and woke up at three in cold sweat, thinking, "Oh God! What if Vishal's grandmother really did throw him into the river? Then why on earth are we doing all this work? What meaning does it have? Okay, so the Balkalyan Sankul doesn't take children who are disabled and destitute. But I could have tried to put him elsewhere. I should've called Mr Dixit or the DSP. I should have...I should have..." These thoughts made me crazy.

I remembered that Vishal's grandmother carried a cotton bag and she was supposed to take the Maharashtra Express leaving Vishal here. That's all that my memory supported. I suddenly realised that I was tossing and turning, my mind a jumble of agonising images. I picked up the phone. It was five. I knew I shouldn't be calling

Mr Dixit who must've gone to bed just a couple of hours ago. He kept late hours. But I dialled his number anyway and when I heard his voice I told him the whole story, sobbing, in fits and starts. The good man was ready to come to Uchgaon at that ungodly hour and console me. But I told him that instead, he should try and find Vishal and take him either to Bal Kalyan or bring him over to me. He got to work at once. Vadikar Dada, a well-wisher and donor, got Vishal's address from Helpers and took a chance at locating him. They found him, forlorn and sad. My heart danced with joy as I saw the little boy.

It turned out that the grandmother's "I'll dump him in the river" drama was a ploy to get us to take Vishal in. And Vishal's mother was far from dead. She'd married again and gone off somewhere far away...perhaps to give birth to another disabled child.

Vishal soon became a darling of the hostel. Young as he was, he never cried even once. His ways were pleasing and his face had a permanent smile. He made us all laugh, especially



when he would ask our caretaker, Sonatai, “*Ati kya Khandala?*” (a popular Bollywood number suggesting “Will you come with me to Khandala?”) Today he walks on artificial feet holding a walker. He loves to go to the Balvadi School, proudly carrying his lunch box. Soon he would be able to walk with crutches.

It was customary for parents and guardians to take their children and wards away during Diwali holidays and summer vacations. Vishal asked me once in his little child-babble voice, “Didi...ttt...ai, would my papa be coming to take me away for the vacations?”

I felt the tears sting my eyelids. I told Vadikar Dada about little Vishal’s question.

“Oh, is that all? It’s not an issue. I’ll take him home with me.”

I was relieved. Both he and his wife were so loving and generous that I was sure Vishal would be happy with them. They gave him toys, clothes and lots of his favourite foods. He had such a good time that he cried unrelentingly when he was brought back to the hostel. We had a tough time trying to control him till the labourers who were working on the next phase of construction picked him up and mollified him with sweets. This year too, Vadikar Dada took him home during Diwali. Vishal came back happily, arms laden with clothes and toys.

Now it so happened that all of us at the hostel were about to visit Anandvan to see Baba Amte. Excitement ran high and Vishal was excited too. But he developed a fever so we decided to leave him behind. Vishal got wind of the fact that he was not to go. From that moment, he sat in a corner (like when he first came) and stopped talking altogether. So we had no option but to take him along. He was so happy that he started dancing.

Amita Rugge, who’d read Dr Anil Awachat’s article, *Naseema and the Helpers*, came to our hostel to stay with us. She studied hard and had a literary bent of mind. In fact, she won the prize for “Ideal Student” in her very first year. She wrote a poem on Vishal:

*Vishal—a child lovely as he  
How could he be an orphan?  
He snatched a vow of affection*



*From someone ... God knows who  
None would say that here was an orphan.  
For what he got were more than mere handfuls.  
His sweet child-like stammer  
Dd..ii...di, ttaa...ii  
Unc...le, Da...ddda  
So innocent with no ambitions  
I wonder how  
This little pawn  
Became more powerful than the king.*

Vishal was a miracle and a solace. I am so grateful to people like him who come like a soothing balm to heal the pain that we disabled people face. More than once, I’ve wanted to form a circle of extremely disabled people and commit mass suicide. Society’s constant strident “Oh, get rid of them, they are trash,” rings in my ears and assails us every time we take a polio-stricken, paraplegic or dwarfed step. Are you alarmed? Shouldn’t you be when the doors of education are closed to us? And you know who shuts us out? Renowned educationists who believe that our brains are as twisted or as dead as our bodies. When society bans our education, we have to form ghettos where we help each other with very little resources. Have separate schools for the disabled, they say. Why? Why when we have normal intelligence? Should we be proud that we are being given a chance to establish a “School for the Disabled?” On the contrary it’s a crying shame. All “normal” schools should have a policy of including disabled students. Stop looking at our bodies. Give us normal education.

Tai Patil was six when we took her in. Her limbs were weak and she couldn’t even hold her head upright. But she had a lovely smiling face. I had my doubts—would we be able to look after one as young and fragile as she? Never mind, I thought finally. Her body may be devastated, but her smile would rejuvenate us. She was such a tiny creature that she couldn’t even hold a pencil in



her hands. Yet she was ready to leave her parents and live in the hostel to get herself an education in a normal school.

Shobha Gurav was with us since our Kadamvadi hostel days. She was also good looking like Tai Patil. She excelled in everything including fighting and being rude. But I liked her because she was good at cajoling and consoling the kids who cried. The polio in both her legs didn't dampen her ambition to conquer the world. I told her to train Tai to do physical exercises. If Narendra Sharma with his crippled hand could give physiotherapy to others while he himself sat in a wheelchair, then Shobha with her normal hands could do better. And I was right. I was surprised to see Tai, who couldn't hold a pencil during her first quarterly exams, doing so well in her half yearly exams, even in the written tests. Soon she could hold her head straight. She sat in a wheelchair and would eat on her own. She was so propelled by these achievements that she actually set herself new targets and challenges. All credit for Tai's miraculous improvement should go to Shobha's hard work and Sonatai's loving care.

Tai is in class four now. She gets seventy to eighty per cent marks in her annual exams. She manages to get down from her wheelchair and visit the toilet. I was and am stunned to see her determination and perseverance even today.

The hostel worked as a family whose members came to each other's help. Children who used crutches and calipers helped those on wheelchairs to climb up or down the inclines. No one had told them to do it, it came naturally I suppose. That was the culture in the hostel.

One day, a lady donor (who was also our well-wisher) came to visit and stay in the hostel for a few days. Now it so happened that we had employed two women who were not disabled. The rest of the staff was disabled. Both the women were the butt of bitter experiences in their lives but they wanted to put their past behind them. They came to us in order to work and mitigate their increasing loneliness. Apparently, the lady guest found some time to chat with them and asked them about their work. When I came back in the evenings, I loved to sit out in the open, chatting and seeing the children moving about doing their thing. That day the lady donor was also sitting with us.



Suddenly she asked, "Why do you take in such *extremely* disabled people? I was chatting with your women helpers today. I believe they are tired and bored of washing and cleaning day in and day out! Granted you give them a salary, but I think the work is a bit much!"

"Uh...huh" I mumbled, taken aback by shock. Was this lady indeed our well-wisher? How come she gave donations when she felt so hostile towards "extremely" disabled people?

"I'll check with the women," I replied calmly. I called for the two women a little later.

I remembered how they had once refused to wash dirty clothes. Rather than impose upon them a job they didn't like, Shobha, Sonatai, Kavita and myself decided to do it ourselves. Once that happened, the women volunteered to do it again. Now they were complaining to a guest.

"Do you have any problems working here?" I asked looking straight at them.

"No...Didi, no...why?" they mumbled.

"Look, you can leave if you want to. We are brave enough to look after each other, get ourselves educated and even attain some social credibility. We at Helpers have given up everything not just to fill the rooms in the hostel with borderline disability cases and claim financial help. This hostel wishes to contribute to the future of those who are rotting within the four walls of their houses, waiting for merciful death to take them away. The hostel is meant for those who have neither resources nor recommendations. Not to take in the "extremely" disabled? So then why am I here? You'll not let us die nor will you let us live. We're not going to leave this place which is the only home for many of us. Those who can't cope with the work may leave, whether disabled or able-bodied, man or woman, young or old. The same rules for everyone. Whatever's to be done should be done with a smile. The only religion we practice here is that of humanity. And you must've seen for yourselves how we take turns with all the chores—whether it's starting the boilers at four in the morning, preparing the baths, making breakfast, rotis for the lunchboxes, chopping vegetables, cleaning grains, washing clothes and utensils, cleaning the bathrooms and rooms and a hundred other things. The older ones who don't go to school clean the grains



and water the plants. Everyone here *earns* his or her keep. I should perhaps inform you that visitors are amazed at how we have maintained such a high standard of cleanliness, something that even a small family doesn't do sometimes. Our secret is that we don't have paid employees. You can see for yourselves how the male students do the cooking on Saturday afternoons and the girls on Sunday mornings so that the staff gets a break. And should we not feel proud that almost all our students pass their exams with good grades? In spite of all this, if you feel exploited, you must go!"

I ended my long speech and took a few deep breaths.

Building the hostel and getting it to its present condition was extremely stressful. It was particularly difficult during the first phase of the construction. At times I would feel totally depressed. Now the hostel had started functioning and we had to repay a loan of seven and a half lakhs. I was stuck, not knowing which way to turn. But one day, help came in the form of Sister Pushpa, the Spanish sister with whom I developed a close friendship during Narendra's treatment. She asked me to apply to a donor in Spain, Manos Unidas. Pramod Beri, our architect, put in a recommendation.

Then we heard from them. They offered to give us funds for the second phase of construction. But we informed them that we couldn't even *start* the second phase till we repaid our loan. So they sent us seven and a half lakhs. Then they asked us to send the complete budget for the remaining construction and proceeded to give us sixty lakhs in two installments. Was this God's reward to us for helping Narendra with his rehabilitation process? I have been repeatedly dumbfounded by how help keeps coming to us whenever we need it most. Now the construction is complete. We have a proper garden as well as a kitchen garden. Our dream of a multi-faceted playground is yet to come true.

Almost coinciding with Narendra's departure from Kolhapur was Aziz's arrival from the Gulf after twenty years of working there. Seeing how overloaded with work I was, he decided to pitch in. He started looking after the training centre and the gas agency and things picked up in both places. We started making wheelchairs along the lines of some high quality ones from abroad. Now we make tricycles, walkers,

commodes, calipers and our own wheelchairs. The latter are still a bit fragile, but we are working on making sturdier ones.

As soon as the children are admitted in the hostel, Dr PG Kulkarni does a thorough medical check up when he decides who needs surgeries. We have an Out Patient Department where we get a few patients whose surgeries are done by Dr Navare and Dr Mahesh Prabhu. Our efforts are to reduce the degree of disability and sow the seeds of self-confidence. The results are sometimes so dramatic that some of our children actually tell the doctors, "Me first, please take me in first for the operation."

Once, as I was in a rickshaw passing by the Saraswati Talkies, I saw a man, one of our earlier beneficiaries, walking on broken crutches. He was going to a dispensary with his wife and kids. I stopped and asked him to get into the rickshaw. On the way we got talking. He was trained in carpentry but couldn't get enough work in his village. I asked him to come over and gave him a good pair of crutches. Actually, I'd been toying with the idea of employing a carpenter in our training centre since the old one had left. So I asked him if he would like to join us and he was only too happy to agree. But he needed some training to make modern furniture and Aziz arranged it. Now when people see his tables and cabinets, there's the inevitable question, "These are great! Who's the carpenter?"

Once, Prof DN Dhanagare, the Chancellor of Shivaji University admired one of the tables and inquired how much it was.

"Oh, so we can actually *sell* them, why not?" I thought to myself. This could be another way of getting self-reliant.

The hostel was now in its fourth year. In the very first year we got Mukta, the main cook, married to Sanjay Deshpande. Mukta walks with a crutch. She has no father and her mother is a psychiatric patient. Though for a person of her background it was difficult to leave her native village, Mukta was courageous enough to do so and live with us. With the salary she gets from us she looks after her younger brother. Sanjay Deshpande, crippled in both hands and feet, has a good job with the irrigation department and in his spare time, gives tuitions in accountancy. He is hard working and kind.





Fortunately for him, his mother and sisters were very supportive of his marriage and continue to help him. Just recently, I attended the naming ceremony of their little child, a healthy, "normal" one.

I'd mentioned earlier that our hostel runs like a family. Very often, therefore, we act like parents. For Mukta this was her parental home, so Rajani arranged a small function of "Goad Bharana" for her.

Ours is a commune of disabled people. Like all families, we go through our ups and downs. But despite the downs, we seem to be getting closer by the day, our bonds of love for each other getting strengthened by the very tribulations that beset us from time to time.

Usually, when any of our residents are in hospital, we send them special food to tickle their palates which have been rendered numb and devoid of taste with anesthetics, pain killers and other drugs. Once, on the day of the full moon of autumn, we decided to have a huge gathering of disabled people. We experimented with interesting recipes and cooked for three hundred and fifty people. The unanimous declaration was that the food was "lip-smacking delicious." Replete with feasting through the night, the next day was declared a holiday.

We were having our breakfast.

"Was the food sent on time to our children in the hospital last night?" I asked casually.

I got no reply. Instead I saw several heads bent low.

"Oh I see," I said. "You'd forgotten, hadn't you? That's very nice—neither those who cooked nor those who were served remembered to send food across to the hospital." My voice took on a sterner note. "And I'm even sorrier to note that they happen to be roommates of some of those sitting here. I guess this is what you do in your homes—forget your brother or sister in the hospital. Instead of trying to finish the food by distributing it forcefully among yourselves, couldn't you pack it up and take it to them? This is not a dharamshala where travelers rest for a while and carry on. This is a family." By now I was very upset. "No food will be cooked today," I ordered and went to my room.

A few hours later one of our social workers knocked on my door. She asked, "Didi, would you like it if the little kids

in primary school and those that are in post-operative care were to starve?" I'd cooled down a bit by then. The matter was not that serious after all, they did care for each other.

"Okay, cook, but only for them." I was trying hard to be firm.

It was four in the evening. Suddenly I felt a gnawing tug at my heart. "The kids must be hungry....maybe..." I thought. In no time I was in the kitchen making uppit for everyone. The fast was officially declared over.

The book is coming to a close and so it's time to mention some of those who contribute to our work in amazing ways. Each of them has a story which is intricately part of the history of Helpers. Let's look at Sataram, a student of class twelve. He had come for training to our centre and then joined Helpers in a more permanent way. He was a spectacular jack of all trades—he could drive a rickshaw, a mini-bus and a van with equal efficiency as he could do computer jobs. Give him any job regarding the gas agency, training centre, hostel, or bank, whether it was documentation or manual work or decision making, he could do it all.

Surve Kaka, who works at the Mahavir College and who loves the children in Helpers kept goading Sataram to appear for his exams. I was not worried however. Let him take his time. Mere academia does not give you the skills that Sataram had, for that we have to bring about a substantial change in our education system. Sataram did everything so perfectly that for a long time my folks didn't even have an inkling that he was disabled. He could even lift me up and put me on the wheelchair. So they were a little unhappy that he never ate anything they offered him. One day, I noticed that he was not given a spoon. How could he eat with his hands when he didn't have some of his fingers? When I told them they were surprised. They'd never looked at his hands.

Once I had a disagreement with Sataram and I scolded him. He thought he shouldn't be upbraided so severely since he wasn't at fault. But I thought so at the time but who knows? He resigned from Helpers and I accepted his resignation. But



deep down we were both really unhappy about it. Aziz came to know about it and to this day I don't know how he handled it but Sataram took back his resignation. Now he heads the list of those like Sujata Kulkarni, Asha Jamne and others who do heaps and heaps of work whether they are well or ill. Chhaya Desai has a complaint against Sataram—he is careless about taking his medicines on time and ensuring that he has a proper diet. She gets angry with him.

We have many inmates like Sataram. I must tell you about a few of them. Asha Jamne was enthusiasm incarnate. Polio had bent one of her feet badly and she never kept good health. After her graduation exams she came to us for a job. For a start, we took her on, paying only her commuting expenses. When she told us that she'd passed her B Com. exams, we appointed her as a trainee clerk in our credit bank which we'd set up as part of Helpers' efforts at financing entrepreneurial work. She manages everything now—cash, administration and so on. She also lends a hand with the main office and the gas agency. Hard working and adventurous, I suppose she needed the opportunity to handle some of my jobs outside the organisation, but the bank takes up all her time. Once in a while she did accompany me to Mumbai and Delhi. Sometimes when Sonatai is not well or goes on leave, she, along with Sujata Kulkarni and Najima Khan, an able-bodied social worker, stay in the hostel and take care of every thing.

The bank turned out to be a boon for several disabled people. Rajani Karkare-Deshpande is its President and I am the Secretary. Our Handihelp Nagari Sahakari Patsanstha (Handihelp Co-operative Credit Society) scheme can now be called a success thanks to several people who helped it grow. We hope some day it will grow into a proper bank and many disabled people will be employed in it. Asha Jamne gets help from her colleague Anand Mole, whose hand has been affected by polio.

Yunus came to us as a child. He used to tie his crippled legs inside a piece of cloth and hang them around his neck and walked on his hands. Even when he had to climb the upper floors sometimes to attend classes in school, he never complained. His severe physical disability never deterred him from going to any office—be it the Social Welfare Office or

the Municipal Office on the upper floors. He always got the job done. Then he took his B Com degree and learnt to work on computers. He is a great singer as well and entertained us thoroughly on our excursion trips. I have to take him to task occasionally because of his hasty ways which can sometimes cause confusion. He now has a temporary job with the Life Insurance Corporation. Though he has a full time job, he works at Helpers till as late as two o'clock at night and is still alert and bright early in the morning. His mother and brothers who adore him bought him a special "scooty" to save him the strain of using a hand-driven tricycle. He stays back when I work late, always finding something to do. Indeed, what would I do without people like him who help me to refresh, reinforce and reinvent myself?

Mehboob, an introvertish kind of chap who came from an organisation for the disabled in Vanavdi, Pune is tireless and skilled. He uses calipers and makes excellent ones in our training centre. I must also mention Rajendra Khorate, a driver who works at the gas agency and who gives of his time and energy ceaselessly.

Ashwini Mane is one of our students who had to be assisted by her mother when we first saw her. After Dr Satvekar's surgical magic, she now walks with our own calipers. With ninety one per cent marks under her belt for the Higher Secondary Exams, getting admission to the prestigious BJ Medical College in Pune was easy and we now look forward to the day that she becomes *Doctor* Mane! How proud we will be!

Vijay Nalavade was one of those who took our "earn while you learn" scheme seriously. He worked with us for four years while he studied and got himself a degree. Like Sataram he is a manic worker. Now he has a good job at the post office. After work he volunteers as an accountant, keeping late hours. Abhijit Gare and PD supervise the accounts.

Abhijit Gare is now one of our trustees. His posture is bent with one hand resting on one of his legs which is badly polio stricken. He is unfortunately one of those who couldn't have surgery at an early age. I'd taken the young Abhijit myself to Dr Sancheti but it didn't help. He began working with me right since then, so he knew how to handle



responsibilities. When we removed Vinod Patel, Abhijit joined the Committee. He took over the gas agency from Vijay Nalvade when the latter got a job at the post office. Once, as in the case of Sataram, I got upset with him and scolded him. He took it so much to heart that he fell ill and subsequently resigned from the Committee. I felt so bad that I went to his place to cajole him.

"Didi, you can hit me, but you shouldn't have said such things to me," he said.

I must admit that I do lose control of what I say when I get upset. Then I have to take back my words. But if truth be told, the casual approach, indiscipline and irresponsibility of young people is something that tilts my tolerance levels. Anyway, Abhijit is doing his law after his B Com. and he manages to support his family after he lost his father. The chatterbox Abhijit of the past has become mature.

Chhaya Desai, another trustee who uses a caliper, faced many obstacles but didn't lose heart. Eventually she became a doctor and now has her own practice. Her only regret is that she doesn't have enough time for Helpers. Chhaya can be a bit short tempered but that never keeps her from rushing to help whenever I need her. I'm always amazed at how methodical she can be. She has a fine hand unlike most doctors whose writing one can never read! She is a good singer too. I'm waiting for the day that she gets well established in her profession and treats the inmates of our hostel.

I must make a special mention of Suresh Shipurkar and Avinash Vadikar. They are just there...always. Avinash supplies milk, beds and mattresses to the hostel. Besides the financial part, he is a "helper" in the real sense of the term. His car is often used to ferry our students to the hospital (sometimes out of Kolhapur) at the oddest hours. And he never sends drivers but comes himself.

"How come you people call me only when there's a crisis and never otherwise?" was his rather pleasant complaint.

When we smile he says, "Oh well, why do you think I bought a Maruti car when a scooter was enough for my purposes? You see, I'd foreseen that you'd call me only when there was a crisis," he joked. He even took our little Vishal to his home for the last two vacations.

And what can I say about Shreekant Kekde, another of our trustees? He has little to do with disability—he doesn't even have a distant disabled relative! But his self-effacing devotion to Helpers is simply amazing. A lawyer by qualification, he is an inspector in the Central Excise Department. He can be called on, well, for anything really, whether it is public relations, documentation or any other odd job. I am always even more grateful when *able* people work with us.

Irshad Hurzuk, dear Irshad is my sister-in-law. Would you mind if I praised her a little more not because she is my sister-in-law but to fully acknowledge her dedication? She is an inveterate "pleader," constantly pleading to people for donations in kind. With her better communication skills she often succeeds. She's a versatile cook, and her culinary expertise covers Indian, Mughlai and continental food. When we have special guests, she takes up the responsibility of catering. Sharfuddin Kapdi, owner of Mera Hotel once gave her fulsome praise, "Even we can't make such food in our hotel!"

Khan Saheb, my brother-in-law from Mumbai and another trustee is someone I've mentioned often in this book. He manages all our work outside Kolhapur.

I say without hesitation that Helpers rests on four strong pillars—PD Deshpande, Rajani Karkare, Manohar Deshbhratar and Shreekant Kekde.

Whatever I say about my younger brother Aziz will never be enough. In the first place, without him, I would never have crossed the threshold of my house, for it was he who bought me my wheelchair. It was he who took me to Mumbai to see the waves of the ocean for the first time. The word Aziz means "dear one." And he is just that—dear to everyone in the family. Getting away—whether it is a trip to the ocean or to see the Taj Mahal or drive along the courtly splendor of Delhi's wide roads—helps us forget our disability for a brief while. Helpers like Subodh Mungle, Vijay Sable, Nashikkar, Deshbhratar, Kekde, Shivaji Patil and others take our trips seriously and give meaning to them. Photographer Anil Velhal captures us on film.

What a family we have—even Anant Dixit, Editor of the prestigious *Sakal*, and the Assistant Editor, Shivaji Patil, whom we thought beyond our reach, is now one of us. Able social worker



Najima Khan is involved in everything—the gas agency, medical camps, trips and so on. Always smiling, she helps me as well as other extremely disabled people bathe, change, cook and stitch.

Then there is Vijaya Patil, my colleague at work. Her husband, an alcoholic, was my colleague too. He used to work with Helpers but his alcoholism destroyed everything and it eventually killed him. Vijaya took his place at the office and proved to be a quick learner. She now supports her old mother and takes care of her daughter. Vijaya and I discussed my writings and it was she who helped me make final drafts, sometimes suggesting, “Didi, let’s put it this way,”...or “Oh, this seems out of place, let’s remove it from here,” and so on. She knows that I’m always overloaded with work, so on weekends she comes to the hostel and supervises the provisions, stores, rooms, bathrooms and various reports. At times she even takes leave from office to give me a hand with functions or looking after guests. She’s truly my friend and I’m so lucky to have her as one. When I finally resigned from my job she cried for many days because she wouldn’t be meeting me everyday.

The two Athane painter brothers must be mentioned too. For years they have been making our boards and banners free of charge. Let me also acknowledge Prabha Vahini Kamat, Manjiri Vahini Karkare, Sunil Dhopeshwarkar and Tatyathavale.

If I have missed out anyone, it’s not out of lack of gratitude but a lapse in memory. Helpers is each and everyone of them, and its dreams too are *their* dreams.

I always feel a bit squeamish when people show me too much respect or touch my feet. I feel apprehensive that I may not be able to rise up to their expectations and that things may take a different turn in the future where my actions may not meet with public approval. There is also the possibility of misunderstandings in which whatever good I may have done in the past could be wiped out in an instant and people may want to punish me and perhaps even remove me. I have seen this happen right here in Kolhapur in my thirty years of public life. I am often called to remember *Bilwadal*, the biographical account of the late Shivajirao Patwardhan written by his daughter, Anutai Bhagvat. A social worker should be prepared to work within a limited time frame and retire from public life and social work when it is the right time. It’s always better

to say goodbye when one is still effective and wanted rather than getting kicked out by others. It hurts to leave something that one has built up so painstakingly over so many years but it is equally important to save oneself from insults and the ensuing bitterness. At this point, I would gladly hand over my presidency to someone else and be a simple worker. I would gladly retire from this responsibility just as I gladly resigned from my job. Alternatively, I would rather slip away into eternal sleep. God forbid that an astrologer’s predictions that I would live up to the age of eighty should come true!

My family often asks me, “Naseem, what would you do if you stopped working with Helpers?”

“Oh! That’s the least of my problems. I would collaborate with those who are like-minded and continue helping them with vocational training. Then I have my own hobbies, so many of them—reading, making pen friends, embroidery, knitting, stitching, cooking and travel. I would also want to continue writing—continuing that which may have been missed out in this book. It’s not important if it never gets published. And if it does, how does it matter, for I won’t be around to face the consequences if there were some! But whoever publishes my work should see that no one is hurt.

It is futile to worry about Helpers when I retire, for any organisation worth its salt should not rest on any one person. Work must and will go on. Who are we to worry? God is there to decide one way or other.

Before I conclude this book, I must recount an episode that illustrates what I mean about social perceptions on this matter. A particular donor had promised to give me a piece of land along with a building for a school and hostel for the disabled. I’d gone to Mumbai a couple of times and completed all the paper work. I was excited because now I wouldn’t have to refuse admission to any disabled student. I was neck deep in my dreams and wildly happy. I went to the donor with all the papers. Earlier, when he’d said, “We are only instruments in His hands, He does every thing, all that I have belongs to Him,” I thought he was like God himself.

But what I didn’t know was that I was to face a rude shock. When the papers were actually presented to him he said, “I’m sorry, but who will manage everything when you



are gone? I can't take the risk. So please bear with me, I can't give you the land and the building."

I tried hard to explain but he wouldn't budge. I felt that familiar sting behind my eyelids and before the tears rolled down, I deftly turned around my wheelchair so that he wouldn't see them. Hadn't Dr Satvekar complimented me on my deftness with the wheelchair? When I left, I was mourning my own death.

I have spondylitis so the doctors advise me not to manoeuvre the wheelchair. But no one tells me how to live without using my hands when I only have hands.

Sataram was waiting for me outside. My heart had plunged into a hole of darkness. I was weeping bitterly in the rickshaw for I had the unbearable premonition that my dreams are about to be shattered one by one. I had no words for poor nonplussed Sataram. He didn't ask either, I think he understood.

Despite all the setbacks I still dream. In my dreams I see the able and the disabled attending the same educational institutions and helping each other. I see better R & D facilities for research and production of prostheses and appliances. I see more compassionate homes for the destitute disabled. I see disabled people forming a commune of fortitude where he or she can find a life partner and lead a fulfilled life.

Actually, my dreams are higher than the skies. It's true that I've got many awards for my work (which I have ploughed back into Helpers) but I also feel awkward that I should be the one to receive them and not each and everyone who has made Helpers possible. I always ask them to award *Helpers*, not me. One day it will happen and I look forward to that.



## HELPERS OF THE HANDICAPPED

Founded by Naseema Hurzuk, this is an organisation registered in 1984 as a Society and a Public Trust. Its primary aim is true and complete rehabilitation of the physically challenged by helping them to become self-reliant persons living with pride and dignity. Helpers provides them the opportunities that are necessary for their development like medical surgeries and aids/appliances, exposure to sports and cultural activities, vocational training and employment opportunities.

At their hostel-cum-rehabilitation centre in Kolhapur, which caters to poor children from rural areas, they have undertaken the complete rehabilitation of hundred and thirty-five disabled children. Their Vocational Training Centre has been successfully producing wheelchairs, tricycles, calipers, crutches and other aids and appliances. This Centre is totally manned by the physically challenged.

### CURRENT PROJECTS

- **Dilasa**—A resident centre for mentally retarded and severely handicapped persons at Kanhe, Dist. Pune.
- **Samarth Vidhya Mandir**—A primary school at Kolhapur to accommodate both able and disabled persons.
- **Lajawab**—A mobile canteen with a view to generating employment as well as income as a step towards achieving fiscal self-sufficiency.
- **Swapna Nagari**—A twelve acre peace of land in Sindhudurg district, received as donation from a local resident is being developed as a centre for physically challenged and aged homeless people. The idea is to generate income through farming and allied food products as well as creating employment opportunities. The project is aimed at accommodation two hundred and fifty disabled people of various categories.

#### AWARDS TO NASEEMA

- B J Modi Foundation Award, 2002 by NASEOH.
- Kolhapur Bhushan, 2002.
- Cavin Kare ability award for Eminence, 2002 by Ability Foundation, Chennai.
- National Award for a Role Model, 2001 by the Ministry of Social Justice and Empowerment, Government of India.
- Baya Karve Puraskar, 1998-99 awarded by the Maharshi Karve Stree Shikshan Sanstha, Pune.
- Fie Foundation Award, Ichalkaranji, 1996.
- Best Lady Entrepreneur of Kolhapur, 1998-99
- National Award, 1986 by the Handicapped Welfare Federation, New Delhi.

#### APPOINTMENTS

- Member of Expert Committee on Disabled Women under the National Commission for Women.
- Member of the committee under the National Trust for the Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities, by the Ministry of Social Justice and Empowerment, Government of India.
- Special guest at the International Year of Women's Empowerment celebrations, 2001, held in New Jersey by the Maharashtra Foundation.
- Member of the Advisory Committee for Women's Study Centre, Shivaji University.

#### CONTACT:

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